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Maarit Karhula

Participation in Everyday Life of People with Multiple Sclerosis

UNIVERSITY OF JYVÄSKYLÄ

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ABSTRACT

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Multiple Sclerosis (MS) is a progressive and unpredictable disease that presents sufferers with multifaceted challenges in participation in everyday life. The main purpose of this dissertation was twofold: first, to explore the participation and perceived functioning of moderately and severely disabled people with MS in everyday life, and second to investigate the effect of a two-year multidisciplinary rehabilitation on everyday activities. This dissertation is based on data from a multidisciplinary group rehabilitation project for people with MS (n=113). Additional data (n=89) collected to evaluate the psychometric properties of the Finnish version of the Impact on Participation and Autonomy (IPA) questionnaire and predictors of participation using structural equation modelling (SEM). Participation and activities in everyday life were studied with the IPA questionnaire and the semi-structured interview Canadian Occupational Performance Measure (COPM), which are both self-assessment measures. The framework of the International Classification of Functioning, Disability and Health (ICF) was applied in the analysis. Improvement in performance in daily activities of the people with moderate and severe MS during the two-year multidisciplinary group rehabilitation was investigated with the COPM using repeated measures of analysis of variance. The results showed that the IPA is a valid and reliable measure that captures the autonomy aspect of participation of people with MS. In addition, perceived problems in participation and activities in daily life of people with MS supported the ICF comprehensive and brief core sets for MS. The results of the SEM indicated that quality of life and the psychological and physical impacts of the disease were the main predictors of participation and autonomy. The two-year multidisciplinary group rehabilitation improved performance and satisfaction with daily activities of people with both moderate and severe MS. The most noteworthy self-reported reasons for change during rehabilitation program were personal and environmental factors. Overall, the findings highlight both the diversity of experiences of participation and activities in everyday life of people with MS and that these experiences are not explained by disease severity. Therefore, self-assessment measures are recommended for measuring participation and activities in everyday life of people with MS. Moreover, the findings suggest that changes in performance and satisfaction in daily activities require long-term multidisciplinary rehabilitation.

Keywords: multiple sclerosis, rehabilitation, participation, ICF classification

TIIVISTELMÄ (ABSTRACT IN FINNISH)

Karhula, Maarit
MS-tautia sairastavan henkilön osallistuminen arjen toimintaan
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Multippeliskleroosi (MS) on etenevä ja ennustamaton sairaus, joka aiheuttaa MS-tautia sairastaville monenlaisia haasteita arkielämässä. Väitöskirjassa tutkittiin keskivaikeaa ja vaikeaa MS-tautia sairastavien osallistumista arjen toimintaan sekä heidän arjen toiminnoissaan tapahtuneita muutoksia kaksivuotisen monialaisen ryhmäkuntoutuksen aikana. Väitöskirja perustuu MS-tautia sairastavien (n = 113) monialaisen ryhmäkuntoutusprojektin aineistoon ja lisäaineistoon (n = 89), joka kerättiin suomenkielisen IPA-kyselyn psykometrisien ominaisuuksien arvioimiseksi. IPA-kyselylomakkeen rakennevaliditeettia ja osallistumista ennustavia tekijöitä tutkittiin rakenneyhtälön mallinnuksella (SEM). Osallistumista ja arkielämän toimintoja tutkittiin kahdella itsearviointimenetelmällä: IPA-kyselylomakkeella ja Canadian Occupational Performance Measure (COPM) haastattelumenetelmällä. Aineistojen analyysissä hyödynnettiin kansainvälistä toimintakyvyn, toimintarajoitteiden ja terveyden (ICF) luokitusta. Kaksivuotisen monialaisen ryhmäkuntoutuksen aikana tapahtuvaa edistymistä arjen toiminnoissa arvioitiin COPM-menetelmällä. Keskivaikeaa ja vaikeaa MS-tautia sairastavien henkilöiden edistymisen vertailussa käytettiin toistomittausten varianssianalyysiä. Tulokset osoittivat, että IPA on luotettava arviointimenetelmä kuvaamaan MS-tautia sairastavien henkilöiden osallistumista autonomian näkökulmasta. Lisäksi tulokset MS-tautia sairastavien kokemista osallistumisen ja toiminnan ongelmista validoivat ICF-luokituksen MS-taudin laajan ja lyhyen ydinlistojen suoritukset ja osallistuminen –alueen listan. Rakenneyhtälömallin tulokset osoittivat, että elämänlaatu sekä sairauden koetut psyykkiset ja fyysiset vaikutukset olivat tärkeimmät ennustajat osallistumiselle. Kaksivuotinen monialainen ryhmäkuntoutus edisti sekä keskivaikeaa että vaikeaa MS-tautia sairastavien toiminnoista suoriutumista ja tyytyväisyyttä. Merkittävimmät itse ilmoitetut muutoksen syyt liittyivät yksilö- ja ympäristötekijöihin. Yhteenvetona tulokset nostavat esille MS-tautia sairastavien osallistumiseen liittyvien kokemusten ja toimintojen moninaisuuden arjen elämässä. Nämä kokemukset eivät ole selitettävissä sairauden vaikeusasteella. Tämän vuoksi on suositeltavaa käyttää itsearviointimenetelmiä osallistumisen ja arjen toiminnan kokemusten esille saamiseksi. Lisäksi tulokset viittaavat siihen, että arjen toiminnoista suoriutumisen ja tyytyväisyyden edistäminen vaatii pitkäaikaista, monialaista kuntoutusta.

Avainsanat: multippeli skleroosi, kuntoutus, osallistuminen, ICF-luokitus

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Jyväskylä 9.8.2020
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FIGURES

TABLES

LIST OF ORIGINAL PUBLICATIONS

The thesis is based on the following original publications referred to in the text by Roman numerals I-IV. Some unpublished findings are also presented.

I. Karhula M, Salminen A-L, Hämäläinen P, Ruutiainen J, Era P, Tolvanen A. Psychometric evaluation of the Finnish version of the impact on participation and autonomy questionnaire in persons with multiple sclerosis. Scandinavian Journal of Occupational Therapy, 2017; 24 (6): 410-420.

II. Karhula M, Kanelisto KJ, Ruutiainen J, Hämäläinen P, Salminen A-S. The activities and participation categories of the ICF Core Sets for multiple sclerosis from the patient perspective. Disability and Rehabilitation, 2013; 35 (6): 492-497.

III. Karhula M, Tolvanen A, Hämäläinen P, Ruutiainen J, Salminen A-L, Era P. Predictors of participation and autonomy in people with multiple sclerosis. American Journal of Occupational Therapy, 2019; 73 (6): 7304205070p1-7304205070p8.

IV. Karhula M, Kanelisto K, Hämäläinen P, Ruutiainen J, Häkkinen A, Era P, Salminen A-L. Self-reported reasons for changes in the activities of daily life during two-year MS rehabilitation. Submitted.

The first author was supported in the original publications listed above as follows. In studies I and III, the first author was supported in structural equation modelling by Professor Asko Tolvanen and in studies II and IV, Katja Kanelisto MSc was co-researcher in the qualitative analysis. In all studies, the first author contributed to designing the studies, had a significant role in data collection and coordination, and drafted the manuscripts. The first author was not involved in the delivery of the rehabilitation program.

ABBREVIATIONS

CIS	Clinically isolated syndrome
CFA	Confirmatory Factor Analysis
COPM	Canadian Occupational Performance Measure
EDSS	Expanded Disability Status Scale
ICF	International Classification of Functioning, Disability and Health
IPA	Impact on Participation and Autonomy questionnaire
MRI	Magnetic resonance imaging
MS	Multiple sclerosis
MSIS-29	Multiple Sclerosis Impact Scale – 29
PPMS	Primary progressive multiple sclerosis
RRMS	Relapsing-remitting multiple sclerosis
RCT	Randomized controlled trial
RM-ANOVA	Repeated measures analysis of variance
SEM	Structural equation model
SPMS	Secondary progressive multiple sclerosis
WHO	World Health Organization
WHOQOL-BREF	World Health Organization Quality of Life assessment

CONTENTS

ORIGINAL PUBLICATIONS

1 INTRODUCTION

Multiple Sclerosis (MS) is the most common neurological disease diagnosed in young adults (Brownlee et al. 2017). It is a degenerative and inflammatory autoimmune condition of the central nervous system (Compston & Coles 2008). Due to its progressive and unpredictable nature it causes multifaceted challenges in participation in everyday life. Different combinations of the symptoms of MS, such as motor, sensory, cognitive, and affective impairment, temperature sensitivity, bladder dysfunction, and painful spasm (Compston & Coles 2008), have a marked effect on the daily life of people with MS and their possibilities to participate actively in social activities and the community (Einarsson et al. 2006). Typically, symptoms fluctuate daily and individually (Kratz et al. 2017), a situation which underlines the importance of a person-centered approach in seeking to identify needs for support in in self-care and in productive and leisure activities.

A person suffering from the symptoms of MS and experiencing problems in daily life caused by the disease can be supported by a multidisciplinary approach to rehabilitation. In such cases, the International Classification of Functioning, Disability and Health (ICF) is commonly used. Since the publication, in 2001, of the ICF, the effects of the environment on functioning, and the meaning and measurement of participation have come to be better understood and taken into consideration in clinical practice (Madden & Bundy 2018). The practical tools of the ICF, such as the comprehensive and brief core sets for MS (Coenen et al. 2011), provide a framework to evaluate the functioning of people with MS and to plan and to conduct appropriate rehabilitation interventions.

The current rehabilitation paradigm emphasizes participation in daily life as a primary goal. For people with MS, this means that different kinds of rehabilitation interventions should focus on helping people to live with the disease and maintain a higher level of independence and self-empowerment (EMSP & R.I.M.S. 2012). Participation has been recognized as a complex phenomenon and hence, in addition to the ICF, many other definitions of participation exist (Dijkers 2010, Fougeyrollas et al. 2019). However, the participation measure used should capture this multifaceted phenomenon in a valid way. In the case of people with MS, the instruments used to measure participation in daily life should be based on individual variation in experiences of restrictions on participation (Månsson Lexell et al. 2006, Lexell et al. 2014) and on individuals' resources.

The main purpose of this dissertation was twofold: first, to explore the participation and perceived functioning of moderately and severely disabled people with MS in everyday life, and second, to investigate the effect of a two-year multidisciplinary rehabilitation on everyday activities.

2 REVIEW OF THE LITERATURE

2.1 Multiple Sclerosis (MS)

2.1.1 Epidemiology and disease course

Multiple Sclerosis (MS) is a degenerative and inflammatory autoimmune condition of the central nervous system with a disabling, progressive and unpredictable course (Compston & Coles 2008). MS is the most common neurological disease diagnosed in young adults (Brownlee et al. 2017). The estimated global number of people with MS was 2.1 million in 2008 and 2.3 million in 2013 (Browne et al. 2014). In 2013, the global median prevalence was 33 per 100 000. The cause of this increase in prevalence is unknown (Multiple Sclerosis International Federation 2015).

Prevalence varies considerably worldwide (Multiple Sclerosis International Federation 2015). In 2016, the highest age-standardized prevalence of MS was in high-income North America, Western Europe and Australasia (165, 127 and 91 per 100 000 respectively) and lowest in eastern sub-Saharan Africa, central sub-Saharan Africa and Oceania (3.3, 2.8 and 2.0 per 100 000 respectively) (Wallin et al. 2019). In addition, it has been shown that even in a high-prevalence area, such as Sweden, the prevalence increases with each degree of latitude northwards (Ahlgren et al. 2011). A recent Finnish study, where, as in the other Nordic countries, the prevalence and incidence of MS is very high, found a higher risk for MS in southwest Finland (prevalence 275/100 000 persons) than in North Karelia in east Finland (prevalence 167/100 000 persons) (Pirttisalo et al. 2018).

Prevalence studies have shown that the approximate ratio of women to men is 2:1 (Multiple Sclerosis International Federation 2015, Wallin et al. 2019), although ratios as high as 3:1 have also been reported (Reich et al. 2018), especially in Europe (Kingwell et al. 2013).

It is suggested that both genetic and environmental factors contribute to MS risk. According to an umbrella review of systematic reviews and a meta-analysis of environmental risk factors and MS (Belbasis et al. 2015), the strongest consistent associations of MS have been found with a biomarker of the Epstein-Barr virus (anti-EBNA IgG seropositivity), infectious mononucleosis, and smoking. However, better-designed studies are needed to establish robust evidence (Belbasis et al. 2015).

The McDonald Criteria, revised in 2017 (Thompson et al. 2018), are the most commonly used diagnostic criteria for MS (Multiple Sclerosis International Federation 2015). The diagnosis of MS is increasingly being based on paraclinical tests (Thompson et al. 2018) of which Magnetic Resonance Imaging (MRI) is an essential component (Wattjes et al. 2015). However, to be optimal, a diagnosis continues to require a specialist clinician (Wattjes et al. 2015), especially for differentiating the patients with a progressive form of MS from those with a nonprogressive disease (Fox 2016). To establish a diagnosis and the disease course, the onset and evolution of the symptoms should be assessed carefully, and previous neurological symptoms that could indicate an earlier unrecognized attack noted (Brownlee et al. 2017). Mean age at onset of MS is 30 years, although up to 5% of people with MS notice their first symptoms of MS in childhood, and in most cases the symptoms are of relapsing-remitting MS (Brownlee et al. 2017). The number of diagnoses of children and adolescents with MS has increased since criteria for the diagnosis of pediatric MS were introduced in 2007 (Krupp et al. 2013).

Four basic MS disease courses have been defined: clinically isolated syndrome (CIS), relapsing-remitting MS (RRMS), secondary progressive MS (SPMS) and primary progressive MS (PPMS). All four courses can be defined as not active or active and, in addition, as progressive courses with or without progression (Figure 1) (Lublin et al. 2014).

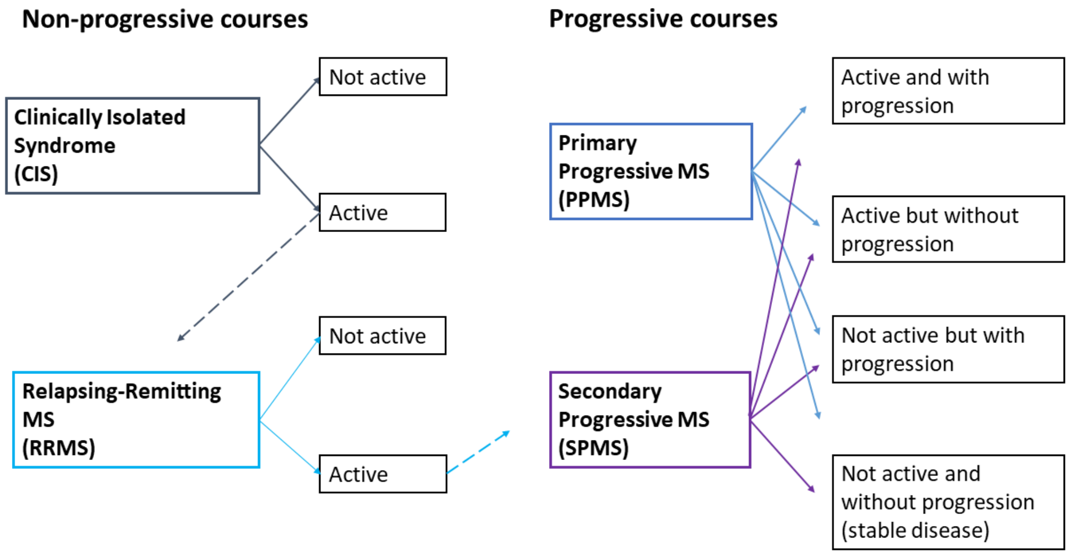


FIGURE 1 Disease courses of MS (modified from Lublin et al. 2014).

Clinically isolated syndrome (CIS), which has been recognized as the first clinical presentation of MS, was added as a description of the clinical course of MS in 2013. In the CIS phase, characteristics of inflammatory demyelination can be observed and hence there is a high risk for MS (Lublin et al. 2014).

Relapsing-remitting multiple sclerosis (RRMS) is the most common type of MS diagnosis, and accounts for approximately 85% of people with MS (Multiple Sclerosis International Federation 2015). Relapses (or the synonyms attack, exacerbation or clinically isolated syndrome, when it is the first episode) are defined as episodes of neurological dysfunction lasting at least 24 h, with or without recovery, in the absence of fever or infection (Thompson et al. 2018). It has been proven that relapses are associated with the occurrence of long-term disability, which increases the need for treatments that reduce the number and severity of attacks (Goodin et al. 2016). Effective treatment for RRMS requires accurate diagnosis (Brownlee et al. 2017). Moreover, continuing clinical evaluations (neurological status, symptomatic assessment, patient well-being) provide essential information when choosing appropriate and timely treatment (Gallo et al. 2015).

RRMS is estimated to develop into secondary progressive MS (SPMS) in up to 80% of cases (Multiple Sclerosis International Federation 2015). In most of these cases, the SPMS diagnosis is made retrospectively after a history of gradual worsening. No clear criteria exist for determining the transition point from RRMS to SPMS (Lublin et al. 2014).

Primary progressive multiple sclerosis (PPMS) is diagnosed in approximately 10 % of persons with MS. PPMS is characterized by the slow progression of neurological disability over time, usually without relapses (Lublin et al. 2014). The diagnosis of progressive MS has been found to be challenging, both in cases of PPMS and in cases where RRMS has transitioned into SPMS (Ontaneda & Fox 2015).

Descriptions of the clinical course of MS are important for communication, prognostication, the design and recruitment of clinical trials, and treatment decision-making (Lublin et al. 2014). In the McDonald criteria (revised 2017), it is recommended that the phenotype should be re-evaluated based on information accumulated, for example during the previous year, to determine if the course is active or progressive (Thompson et al. 2018).

An individual’s disease course is unpredictable. Typically, people with MS live with a progressive, unpredictable neurological disease for many decades. Life expectancy with MS is approximately seven to fourteen years lower than in the general, healthy population (Scalfari et al. 2013). A Canadian study found that although the survival of people with MS has improved over time, it has remained lower than that of the population without MS. Comorbidities have increased mortality, as they have also done for the population without MS (Marrie et al. 2015). Because of increased longevity, efforts to develop and provide appropriate care for larger numbers of people with high levels of disability is needed (Scalfari et al. 2013).

2.1.2 Symptoms of MS and contextual factors that influence functioning in everyday life

MS symptoms vary considerably according to the location of the lesion, which may be in the cerebrum, optic nerve, cerebellum and cerebellar pathways, brainstem, spinal cord or other areas (Compston & Coles 2008). Common symptoms are cognitive impairment, hemisensory and motor impairment, affective states (such as depression), unilateral, painful loss of vision, tremor, clumsiness or poor balance, diplopia, oscillopsia, vertigo, impaired swallowing, impaired speech and emotional lability, paroxysmal symptoms, weakness, stiffness and painful spasm, bladder dysfunction, erectile impotence, constipation, pain, fatigue, temperature sensitivity and exercise intolerance (Compston & Coles 2008). Different combinations of these symptoms have a considerable effect on the daily activities of people with MS and their possibilities to participate actively in social activities and the community (Einarsson et al. 2006).

The impact of the disease on functioning in everyday life can be physical, such as problems using different means of transport, and psychological, such as worries related to the disease (Johansson et al. 2007). In addition, social activities and participation can be disrupted, especially by MS-related cognitive disorders (Hughes et al. 2015, Cattaneo et al. 2017). There is also a risk for reduced communicative participation, especially in the case of persons with reduced cognitive and speech skills, lower levels of speech usage, limitations in physical activities and higher levels of education (Yorkston et al. 2014). MS also influences work-life. Work-related difficulties, for instance unemployment, lower working hours or job cessation are affected not only by symptoms of the disease but also by contextual factors such as social, attitudinal, and policy factors (Prodinger et al. 2010, Raggi et al. 2016).

Marked individual variation has been found in perceptions of how participation restrictions impact everyday life (Månsson Lexell et al. 2006, Lexell et al. 2014). In addition, self-awareness of the functional status of instrumental activities of daily living and quality of life vary between persons and should be taken into account when planning support in everyday life (Goverover et al. 2009). It has been noticed that different symptoms intersect and that they share several features, which sometimes hampers identification of the factual symptom. For example, depression and fatigue in MS share several features and show a similar longitudinal course (Greeke et al. 2017). Moreover, symptoms fluctuate daily; pain intensity, especially, is related to both daily social and physical functioning (Kratz et al. 2017). A person-centered approach to monitoring and treating symptoms is needed to better understand individual fluctuations (Kratz et al. 2017) and the intersection of symptoms.

People with MS report that limitations on functioning have forced them to continuously struggle to maintain engagement and have made it necessary for them to construct a life different from the one they had before MS (Lexell et al. 2009). Moreover, one example of the complexity of everyday activities and participation is that people with MS experience differences between their ability to execute a task or an action (capacity) and what they actually do in their current environment (performance). People with MS have reported worse capacity than performance, for example in obtaining goods and services, caring for household objects and doing housework. In contrast, they have reported better capacity than performance in activities such as fine hand use, family relationships and intimate relationships (Svestkova et al. 2010).

The complexity of participation is also influenced by the fact that the same environmental factors, such as social relations or physical features of the environment, may be experienced differently by different people (Holper et al. 2010). Moreover, the challenges faced by an elderly person with MS may be different from those faced by younger people (Stern et al. 2010).

In the same way as the functioning of people with MS varies individually and is affected by many factors, so too is quality of life. Perceived quality of life is affected by various factors, such as the level of social support, living area, depression, level of education, employment, fatigue and religiosity (Yamout et al. 2013). Interestingly, the physical but not mental component of health-related quality of life was associated with age, disease duration, severity of disease and social participation (Mikula et al. 2015).

2.1.3 Treatment and support of people with MS

Although no remedial treatment exists for MS, medical treatment is an essential and rapidly developing field. Medical treatment for MS includes disease-modifying therapies (DMTs), drugs to treat MS relapses and medications for MS symptoms such as fatigue, muscle stiffness, pain and bladder or bowel control problems. The goals of DMTs are to reduce the number of relapses, delay progression of the disability, and limit new disease activity, which can be detected using MRI. DMTs depend on the clinical course of MS, and responsibility for beginning and monitoring DMTs rests with the neurology unit. The goal of medical treatment for MS relapses is to relieve relapses that markedly affect functioning (Working group set up by the Finnish Medical Society Duodecim and the Finnish Neurology Society 2020). To enable homogeneity of treatment decisions across Europe, evidence-based clinical practice guidelines for the pharmacological treatment of people with MS are being developed (Montalban et al. 2018).

Rehabilitation is an increasingly recognized aspect of comprehensive MS care. Because MS causes various symptoms and influences many life areas, a multidisciplinary approach is essential in MS rehabilitation. Such multidisciplinary teams consist of different professionals such as a physician who is a specialist in rehabilitation and medical treatment, nurse, physiotherapist, occupational therapist, speech-language therapist, neuropsychologist and social worker (EMSP & R.I.M.S. 2012). Support services for people with MS, such as support groups, printed or audio-visual materials, telephone helplines, websites and newsletters, are essential for receiving disease-specific knowledge and peer support. In addition, as previously mentioned, promoting quality of life also includes supporting family members and caregivers, the availability of accessible homes and public buildings, access to communities through accessible public transportation, and assistive technologies (EMSP & R.I.M.S. 2012, Multiple Sclerosis International Federation 2015).

2.1.4 Goals of MS rehabilitation

Individual goals should be based on individuals’ needs. The need for care-givers should also be considered and compared against the needs identified by the person with MS and close persons (Lorefice et al. 2013). Goal setting is a negotiation process in which the person with MS and professionals together identify the key priorities and agree the target level of attainment within a specified time frame (Playford 2019). The need for individual and patient-reported goal setting is supported by the fact that persons with MS and professionals do not necessarily agree on the goals of rehabilitation. It has also been noted that people with MS may have higher expectations of improvement than professionals, a situation that testifies to the need to negotiate goals during the rehabilitation process (Bloom et al. 2006). Therefore, the process of goal setting has been considered an important phase of rehabilitation (EMSP & R.I.M.S. 2012).

The current rehabilitation paradigm emphasizes participation in daily life as a primary goal. The focus of MS rehabilitation is to help people to live with MS and enhance their ability to carry out everyday activities in new ways so as to maintain a higher level of independence and self-empowerment. The goals of MS rehabilitation differ in the initial and early stage, later stage and advanced stage of the disease. In the initial stage, after diagnosis, the main goal of rehabilitation is the provision of personalized information. Specifically, rehabilitation in the early stage is targeted at managing fatigue and other symptoms as well as providing counselling to promote physical activity and offering aids and ways of adapting the home. In the later stage, the goals are to maximize functional independence while seeking to minimize disability and handicap and ensure the maintenance of the person’s roles in the family, workplace and community for as long as possible. In the advanced stage, the goal is the maintenance for as long as possible of an independent life in the person’s own home and lessening the burden of caregivers. Therefore, rehabilitation focuses on, for example, home modifications and teaching coping methods for both those with MS and their caregivers (EMSP & R.I.M.S. 2012).

In addition to the stage of the disease, the rehabilitation time frame should be considered when setting goals. Goals can be set for the near, mid or distant future. Long-term goals, especially, are preferred at the participation level whereas intermediate or short-term goals usually target changes in the level of activity (Barnard et al. 2010). Owing to the unpredictable and progressive nature of the disease, goals should be flexible and problem-focused. Moreover, those with MS, their close ones and the rehabilitation professional should share an understanding of the goals set and accept them (Kalb 2012).

2.2 ICF classification

The International Classification of Functioning, Disability and Health (ICF) offers a shared framework for multidisciplinary MS rehabilitation. In this section, the purpose and structure of the ICF and its clinical use in MS rehabilitation is described. One of the key concepts of the ICF, and also of this study, "participation" is addressed in more detail in the next section.

2.2.1 ICF – components and structure

The ICF defines functioning as the dynamic interaction between a person's health condition, environmental factors and personal factors (World Health Organization 2001). The ICF incorporates bio-medical, psychological and social models of functioning and disability. Definitions and categories of functioning describing both the positive and negative aspects of functioning from a biological, individual and social perspective are worded in neutral language (World Health Organization 2013).

The ICF presents information in two parts. Part 1 comprises functioning and disability, and is made up of the following two broad components: a) body functions and structures and b) activities and participation. Part 2 covers contextual factors; these are a) environmental factors and b) personal factors (Figure 2). Each component, except for personal factors, which have not yet been coded in the ICF, includes domains (also called chapters), which are further organized into second-, third- and fourth level categories. For example, the activity and participation component contains nine domains comprising 118 second-level categories and approximately 400 third- and fourth-level categories. Altogether, the ICF classification consists of more than 1 400 categories (World Health Organization 2001).

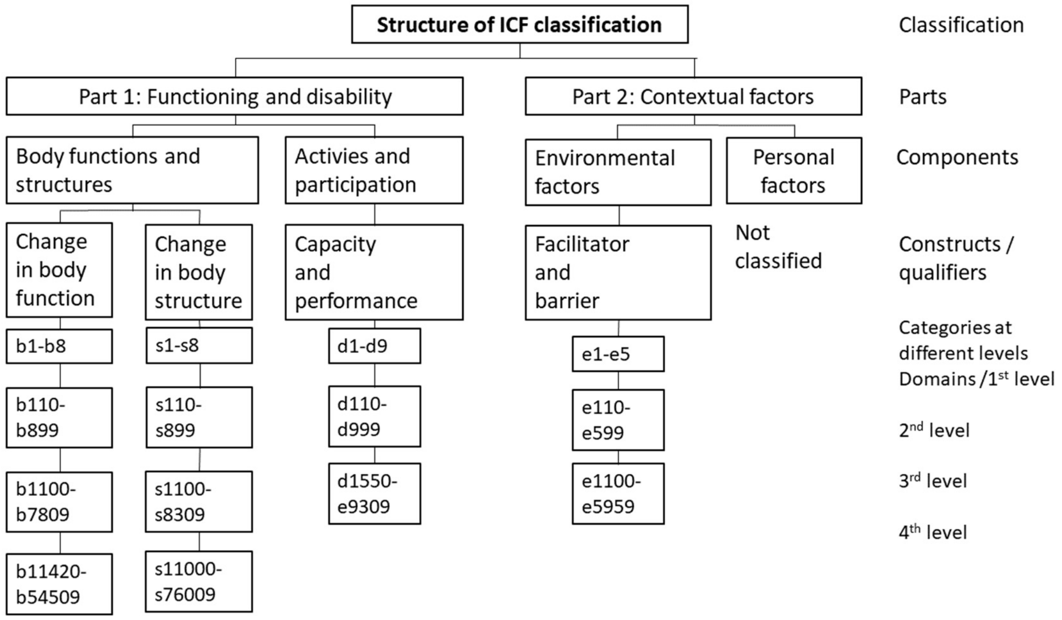


FIGURE 2 The hierarchical structure of the ICF classification (World Health Organization 2001).

Although, the ICF provides a hierarchical model of functioning, it underlines the complex and often unpredictable interaction of different elements. For example, on the individual level, it is impossible to predict how a certain health condition or environmental factor will influence an individual's functioning (World Health Organization 2013). However, the ICF was not designed as a theoretical description of particular instances underlying the processes of interaction. Instead, the ICF provides a conceptual framework for a description of interactions between different components of functioning (Stucki et al. 2015).

2.2.2 ICF – clinical use

The ICF framework can be used for a variety of purposes in clinical practice. First, it provides a common language for various health and social care clinicians and their clients. Second, it offers a holistic framework for multidisciplinary clinicians to evaluate functioning, set goals, plan interventions and communicate. Thirdly, the ICF-based applications unify and organize practice and data on functioning and disability (World Health Organization 2013). Since its publication in 2001, the ICF has influenced on rehabilitation practice in various ways. National surveys, information systems and ICF-based instruments have been developed. The effects of the environment on functioning and the meaning and measurement of participation, in particular, are nowadays better understood and considered in clinical practice (Madden & Bundy 2018).

The ICF checklist is a practical tool for summarizing information on the functioning and disability of an individual. It covers the major categories of the ICF and can be utilized with diverse patient groups (World Health Organization 2013).

ICF core sets have been developed for specific diseases to capture those aspects of functioning that are most likely to be affected by a specific disease. The process of developing the ICF core sets consisted of a formal decision-making and consensus process using knowledge from recent studies and integrating the perspectives of persons with a specific disease and experts on the disease via interviews and surveys (Cieza et al. 2004).

The ICF core sets for MS were developed to stimulate research leading to better understanding of the complex nature of MS-related functioning, disability and health. The core sets are practical tools that cover multiple symptoms and limitations in the functioning of people with MS in their physical, social and attitudinal environment. In addition, the ICF core sets provide a frame for the development of assessment instruments to measure the effectiveness of interventions. Moreover, they serve as a basis for developing interventions that enhance the restoration and maintenance of functioning and minimize disability among people with MS (Kesselring et al. 2008, Coenen et al. 2011b). The comprehensive core set of MS is used when a comprehensive multidisciplinary description and assessment of functioning is needed, and the brief core set when a brief description and assessment of functioning is sufficient (Coenen et al. 2011b).

The comprehensive and brief core sets for MS were developed using data from a systematic review and an internet-based expert survey (Coenen et al. 2011b), along with a focus group of 27 persons with MS (Coenen et al. 2011a). In addition, the applicability of the ICF categories was evaluated for 205 persons with MS as part of a multicentre empirical study (Holper et al. 2010). Moreover, the content of the ICF core sets for MS has been validated from the perspectives of physical therapists (Conrad et al. 2012b), occupational therapists (Conrad et al. 2012a) and speech and language therapists (Renom et al. 2014).

A total of 138 ICF categories were included in the comprehensive ICF core set for MS and 18 categories in the brief core set for MS. The comprehensive ICF core set for MS comprises 40 body function categories, for example memory function and muscle tone function, seven body structure categories, 53 activity and participation categories such as focusing attention, washing oneself and recreation and leisure, and 38 environmental factors categories which cover both physical and social environmental factors. The brief core set for MS comprises eight body function categories (energy, emotions, higher-level cognition, seeing, sensation of pain, urination, muscle power and gait patterns), two body-structure categories (structure of brain and spinal cord and related structures), five activities and participation categories (solving problems, carrying out daily routines, walking, family relationships and remunerative employment) and four environmental factors (family members and their attitudes, health professionals and health services, systems and policies), all of which are also included in the comprehensive ICF core set for MS (Coenen et al. 2011b).

Both ICF core sets for MS warrant further validation and worldwide applicability studies (Coenen et al. 2011). The perspective of people with MS was acknowledged during the process of developing the ICF core sets for MS in one small-scale study (Coenen et al. 2011). In the study, a sample of 205 people with MS identified eleven ICF categories, four of which were included in the brief ICF core set, that best differentiated different levels of functioning (Conrad et al. 2014). There is, therefore, a need to further investigate the validity of the ICF core sets from the point of view of people with MS.

2.3 Perspectives on participation

2.3.1 Participation in the ICF

The ICF classification has played an important role foregrounding participation as an important rehabilitation outcome (Cardol et al. 2002). Activities and participation together are an integral component of the ICF. An activity is defined as action or task executed by an individual and activity limitations are any difficulties an individual may have in executing the activity. Participation is defined as involvement in a life situation and participation restrictions as problems an individual may experience in involvement in life situations (World Health Organization 2001).

However, it is often difficult to determine if an item classified in certain domain and category is connected with ICF activity or participation. The ICF provides four options for differentiating activity from participation (Figure 3). The first option is to use distinct, non-overlapping, sets of activity and participation domains. The first four domains are activity domains and domains five to nine are participation domains. In the second option, the activity and participation domains partially overlap. Thus, domains one and two are categorized as activities, domains three, four, five and six are categorized as both activities and participation and domains seven, eight and nine are categorized as participation. In this dissertation is applied the most widely used third option, in which the same domains represent both activities and participation. The fourth option is that more general or broader categories within a domain (e.g. first-level categories) are interpreted as participation and categories that are more detailed are interpreted as activities (World Health Organization 2001). In this dissertation is applied the third option.

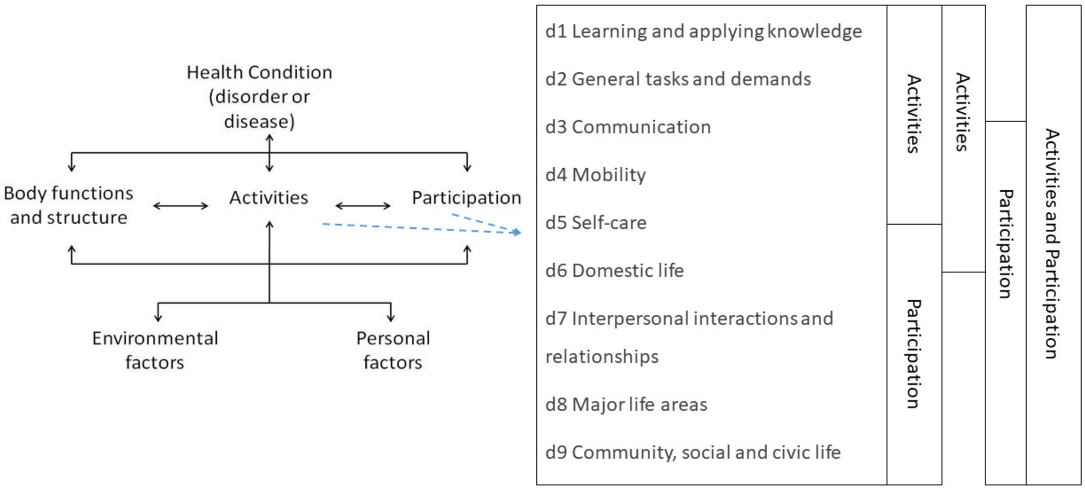


FIGURE 3 Activities and participation in the ICF (World Health Organization 2001).

Activities and participation are described in the ICF with two qualifiers – performance and capacity (Figure 2). Performance describes what person actually does in his/ her current environment and is thus connected with a person's involvement in life situations. Because performance describes interaction between the person and the environment, performance may change in different environments. Capacity reflects the environmentally adjusted ability of the person and is measured in standardized settings. The combining of knowledge about performance and capacity helps determine whether the environment facilitates or hinders a person's performance and provides information on possibilities to improve performance (World Health Organization 2001).

2.3.2 Other aspects of participation

While the ICF provides a widely shared definition of participation, no consensus has yet been reached on the conceptualization of this complex phenomenon (Dijkers 2010). Some studies have criticized ICF-based definitions and in others the definition of participation has been expanded or deepened (Hemmingsson & Jonsson 2005). Moreover, it has been noted that many concepts such as quality of life, well-being and social performance overlap with participation (Babulal et al. 2015).

Four important limitations on the concept of participation may complicate the use of participation in clinical practice: first, the concept is ambiguous; second, the distinction between activity and participation is unclear; third, subjective aspects of participation are lacking; and, finally, there is no mutual agreement about how to measure participation (van de Velde et al. 2018).

Participation as a contextual phenomenon

In the ICF, participation is seen as closely connected with environmental and personal factors. Environmental factors are classified into five domains: e1 products and technology, e2 natural environment and human-made changes to the environment, e3 support and relationships, e4 attitudes and e5 services, systems and policies (World Health Organization 2001). Personal factors have not yet been classified in the ICF. This means that the role of personal factors does not receive the attention it deserves. It is, therefore, important to incorporate into the ICF the findings of studies which have investigated contextual factors and their links to participation.

The data obtained from focus groups, including persons with disability, yielded the following eight categories of environmental factors that impact on participation: the built and natural environment, transportation, assistive technology, information and technology access, social support and societal attitudes, systems and policies, and the economic environment. The data draw attention to factors (e.g. information and technology access, economic quality of life) that are not included in the ICF list of environmental factors. These factors were described as facilitating and/or hindering or enabling and/or disabling participation in different contexts and may have a cumulative influence on participation (Hammel et al. 2015).

The connection between participation and environmental factors proposed by theoretical studies has been empirically supported. However, the size of the contribution of environmental factors to participation has nevertheless been found to be low, and hence further research is needed (Noreau & Boschen 2010). To better understand and regenerate thinking about the complex interaction between participation and environmental factors, the application of ecological, life-span, and life-course models has been suggested. Improved understanding of the environment-participation relationship would help in modifying environments to facilitate the participation of individuals with disabilities (Garcia et al. 2015).

For rehabilitation purposes, environmental factors related to participation at the individual (micro) level, such as home modifications or assistive technology, have been quite well identified. However, environmental factors at the community (mesa) and societal (macro) levels (e.g. economic resources, systems and policies, societal attitudes) can influence participation outcomes as much, if not more, than individual interventions (Hammel et al. 2015).

Moreover, a problem in clinical practice is that outcome measures do not automatically include environmental factors. It has been suggested that it is not necessary to create new tools in order to take environmental factors into account; instead, it would be enough to add information about them to the information provided by the participation measure used (Wee & Lysaght 2009).

Certain important environmental factors have not been included in outcome measures. Climate and seasonal changes are prime examples of factors that are well known to influence participation yet have been little studied. A recent longitudinal study of seasonal patterns, community participation and mobility suggested that accessible physical activity during winter time for people who use wheelchairs should be developed and that wheelchairs should be designed to optimize their use during winter (Borisoff et al. 2018). The effect of social support and social attitudes on participation has also been recognized. As a result, the self-report item pool of social attitudes was developed to highlight aspects of the social environment that can be improved to facilitate the participation of people with disabilities (Garcia et al. 2015).

Participation related to personal factors has been considered in many studies. Personal factors have an important role in enhancing our understanding of functioning, including participation, and in strengthening the perspective of the individual in how the ICF is applied (Geyh et al. 2011). One suggestion has been to organize personal factors into three broad themes: 1) individual-related information, such as socio-demographical factors, position in the immediate social and physical context, personal history and biography), 2) subjective experiences, comprising feelings, thoughts and beliefs, and motives, and 3) recurrent patterns of experience and behavior (Geyh et al. 2019). However, it also been debated whether personal factors should or should not be structured or classified in more detail. It has been argued that a classification of personal factors can be misused as a classification of the individual (Leonardi et al. 2016).

Differentiating participation from social and community participation

The ICF's definition of participation has been criticized for not sufficiently capturing participation from the perspective of societal involvement. Therefore, it has been proposed that the concepts of participation and social participation should be clearly defined and the ICF's definition of participation reoriented towards social roles (Piškur et al. 2014). This, it is believed, would encourage professionals to redesign education, research and practice to better support clients' opportunities to manage their own situations, help each other, and contribute to society (Piškur 2013).

In their content analysis of definitions of social participation in older adults, Levasseur et al. (2010) showed that social participation is defined in most cases as a person's involvement in activities involving interaction with others in society or the community. They propose six levels of involvement according to the main goal of the individual's social activities. These levels are 1) doing an activity in preparation for connecting with others, 2) being with others, 3) interacting with others without doing a specific activity with them, 4) doing an activity with others, 5) helping others, and 6) contributing to society. Participation is realized in all levels, social participation in levels 3 through 6 and social engagement in levels 5 and 6. This analysis of participation, by including different kinds of activities that can be performed for oneself or with others or for others, addresses the multifaceted nature of the phenomenon (Levasseur et al. 2010).

The societal aspect of participation is also emphasized by the concept community participation, which is defined as active involvement in activities that are intrinsically social and occur either outside the home or as part of a nondomestic role. The definition of community participation emphasizes that being in connection with the community does not require physical presence in the community. Moreover, in some situations, non-domestic roles may be enacted at home, for example calling a friend (Chang et al. 2013).

Social participation is also one of the key concepts in the Disability Creation Process (DCP) model, which was first formulated in the 1980s and revised in 2010. In the DCP model, personal factors, consisting of identity factors, organic systems and capabilities, environmental factors on the personal, community and societal levels and life habits, interact with each other. Therefore, life habits, which range from full social participation to situations that allow no social participation, cannot be measured solely from the perspectives of personal or environmental factors (Fougeyrollas et al. 2019).

Participation as a subjective experience

A crucial aspect of participation is the individual's, or so called insider's, experience of participation (Brown 2010). Many studies have yielded a deeper understanding, especially from the point of view of MS individuals themselves, of the multifaceted phenomenon of participation, than that offered by the ICF classification. Insiders' perspectives broaden understanding of participation and guide the development of assessment and intervention methods aimed at improving participation.

In a review on the conceptualization of participation, found ten studies on participation from the perspective of subjective experiences. Thematic analysis yielded six themes: autonomy, belongingness, challenge, engagement, mastery, and meaning (Martin Ginis et al. 2017). Participation from the perspective of people themselves appears to form a cluster of values, indicating that it is not possible to define ideal or optimal participation. An important feature of participation is its two-fold nature as both a right accorded by society and a personal responsibility (Hammel et al. 2008). Insiders' views of participation emphasize the importance of a sense of belonging and having a positive feeling that one is included and can make a difference (Sverker et al. 2019).

It has been recommended that different aspects of participation are incorporated into conceptualizations and operationalizations of the participation construct (Martin Ginis et al. 2017). In clinical practice, a broadening of the definitions given by the ICF would encourage more serious consideration of patients' socio-emotional participation in health promotion (Sverker et al. 2019).

The Family of Participation-Related Constructs (fPRC) framework emphasizes the importance of the subjective experience of participation. It defines participation as attending and being involved in life situations. The concept "attendance" describes participation as presence in the situation, which can be measured as frequency of attendance or as the range or diversity of activities that a person is involved in. The concept "involvement" is defined as an experiential component of participation. In addition to participation from the point of view of involvement as a subjective experience, the fPRC emphasizes that participation can be viewed both as a process and as an outcome of rehabilitation (Imms et al. 2017).

Participation and occupational performance

The concepts of participation used in the models and theories of occupational therapy differ from but also show points of intersection with the ICF. Common to the different occupational therapy models is the definition of participation as lived experience, which is realized in the mutual interaction of person, activity and environment (Mallinson & Hammel 2010a).

In the Model of Human Occupation (MOHO), the concept of occupational participation parallels the concept of participation used in the ICF. In addition, occupational performance in the MOHO means the same thing as activity in the ICF (Kramer et al. 2008).

In the Person-Environment-Occupation model, a person’s occupations and roles, and living, working and playing environments are in a dynamic relationship, termed occupational performance (Law et al. 1996). Similarly, in the Canadian Model of Occupational Performance and Engagement (CMOP-E), interaction between person, environment and occupation results in occupational performance, which is defined as the ability of a person to perform occupations and daily engagements. In the CMOP-E, the concept occupational engagement emphasizes the importance of occupational opportunities. Occupational performance and engagement are closely connected to participation in the ICF (Polatajko et al. 2007).

In the Occupational Therapy Intervention Process Model (OTIPM), participation is a synonym for the concept of occupational engagement. Thus, the OTIPM emphasizes that participation is more than taking part in or doing something or frequency of performance or being able to perform tasks independently. Participation is viewed as a combination of doing and experiencing doing. In addition to these features, participation occurs when the experience of doing has a personal value (Fisher & Marterella 2019). In other words, participation, as a synonym for occupational engagement, involves aspects of meaning, interest, motivation, and/or perceived self-efficacy (Kennedy & Davis 2017).

Moreover, the concepts occupational balance and occupational justice are closely connected with participation and reinforce the understanding of participation as a complex phenomenon. The concept occupational balance refers to various issues that are also relevant when discussing issues of participation. A scoping review of twenty-two studies summarized the crucial features of occupational balance as follows: the inclusion of occupations for their own sake adds the experience of occupational balance, meaning that optimal variation between occupations is needed, and experiences of occupational balance vary across people (Wagman et al. 2015). Occupational balance can be examined from the perspectives of the quantity of involvement across occupations; the conformity of occupations, personal values and goal orientations; the fulfilment of demands of roles; and consistency in the arrangements of occupations (Wagman et al. 2015). Occupational justice is based on the assumption that individuals have unique sets of occupational needs and capacities in particular environments. It emphasizes people's right to engage in diverse and meaningful activities and develop their potential (Durocher et al. 2014).

Participation from the viewpoint of autonomy

Autonomy has been defined as a prerequisite for effective participation, and therefore a primary aim of rehabilitation. Participation from the standpoint of autonomy can be divided into the ability to make decisions without external restraints (decisional autonomy) and the ability to act as one wishes (executional autonomy) (Cardol et al. 2002). However, there has also been debate on whether, in some situations, it might be necessary to limit a person's autonomy. For examples, one person's autonomy may conflict with other people's autonomy or with the person's own interests (Catz & Itzkovich 2002). For clinicians, the issue of autonomy should focus more on enablement, including, for example, coaching, facilitating and educating people than on traditional treatment and caregiving in the sense that these are not done to/for people with disabilities, but instead with them (Chan 2002).

It has been suggested that in the context of a chronic physical illness, the notion of autonomy should include consideration of the gap between what people want their lives to be like and what their lives are actually like. Sense of autonomy can be supported by increasing individuals' opportunities to arrange their lives or by helping them to adjust their horizons to what is feasible (Mars et al. 2008). The perspective of autonomy in participation emphasizes individuals' ability to control their lives. In situations where the ability to perform actions independently is threatened or limited, it is especially important to determine to what extent control over one's life is possible (Perenboom & Chorus 2003).

A few studies have addressed participation in everyday life of people with MS from the standpoint of autonomy. The participation and autonomy of people with MS have been found to be linked to appraisal, defined as the evaluation of a situation or ability to deal with the situation (van den Akker et al. 2016) and to disease severity and generic quality of life (Kwiatkowski et al. 2014).

2.4 Supporting participation in the daily life of people with MS

2.4.1 Evaluation of participation in daily life of people with MS

Measures of participation vary. Some instruments only measure participation while others measure other parameters as well as participation. Some instruments are multidimensional and others unidimensional. There is also variation due to the different conceptual models underlying measures and whether they are objective or subjective in nature. Moreover, measures vary according to their development processes and psychometric properties (Whiteneck 2010).

To update the findings on participation measures in the field of rehabilitation, review articles were searched via Medline Ovid. The search strategy was as follows: participation.mp. or Community Participation/ or Social Participation/ AND measure.mp./or questionnaire.mp or "Surveys And Questionnaires" or instrument.mp. or assessment tool.mp. AND Rehabilitation/ or rehabilitation.mp. or Rehabilitation Research/. The search was limited to articles published between 2009 and April 2019. A total of 19 review articles that systematically analyzed participation measures were identified. Of these, six focused on the participation of children and young people (Phillips et al. 2013, Chien et al. 2014a, Chien et al. 2014b, Rainey et al. 2014, Field et al. 2016, Adair et al. 2018) and hence were excluded from this summary. In addition to the 13 reviews on measures used with adults, five additional reviews were found during the literature review process. Each of the 18 reviews is summarized in Table 1.

Of the 18 reviews, 5 summarize generic measures of participation, 10 summarize measures for people with a specific condition and 3 summarize both generic and specific measures (Table 1). No reviews on measures used with people with MS were found. Two reviews also included measures for children and youth (Resnik & Plow 2009, Seekins et al. 2012). Despite their different target populations, the reviews deal with the same themes.

The overarching theme of the reviews is the conceptualization and operationalization of participation. The definition and conceptualization of participation and factors, such as contextual factors, that are closely connected with participation, were discussed in chapters 2.3.1 and 2.3.2. Participation should be conceptualized and operationalized before construction of the measurement instrument (Dijkers, Marcel P. 2010). This means that the complexity associated with defining of participation is reflected in the measures proposed. Most of the reviews mention the difficulties in defining and conceptualizing participation, although 12 of them subscribe to the ICF definition of "involvement in life situations". In two of these 12, the ICF activity and participating chapters d6 domestic fife, d7 interpersonal interactions and relationships, d8 major life areas and d9 community, social and civic life are interpreted as participation (Noonan et al. 2009, Chung, Yun & Khan 2014). Other definitions for participation used in the reviews focus on social activities or fulfilling social roles (Dalemans et al. 2008, Eyssen et al. 2011b, Seekins et al. 2012, Chang et al. 2013) or emphasize that participation includes complex community-related activities (Brandenburg et al. 2015, Resnik et al. 2017).

The number of measures identified per review varied from 8 to 72, depending on the inclusion criteria. The reviews highlight the diversity of measures. Many reviews conclude that most instruments measure one or more domains of the activities and participation listed in the ICF, but that none of them measure all the domains (Perenboom & Chorus 2003, Mortenson et al. 2008, Eyssen et al. 2011b, Chang et al. 2013, Tse et al. 2013, Engel-Yeger et al. 2018). In one review, it was highlighted that while the measure should represent a broad perspective on the participation domains, different aspects of participation should not be combined into a single overall score (Engel-Yeger et al. 2018).

Despite the large number of measures identified, some reviews concluded that a need remains for a new measure which would better cover, for example, community participation (Chang et al. 2013) or which would focus on specific aspects, such as empowerment (Babulal et al. 2015). In addition, one review revealed that participation measures often include items in which participation is related to other constructs such as activities, impairments or contextual factors (Resnik & Plow 2009). Moreover, one review proposed that the cultural equivalence of participation measures has not been sufficiently tested. Therefore, the cultural equivalence of the participation measures used in clinical practice need to be carefully considered (Stevelink & van Brakel 2013) .

TABLE 1 Reviews of participation measures

First author and publication year	Aim of the review	Population	Definition of concept/ focus of measure	Time limits on search	Number of measures included	Conclusions
Focus on measures for different populations (generic measures)						
Chang 2013	To identify instruments that measure community participation in people with disabilities and to evaluate which domains, to what extent, and how precisely they address this construct.	Generic	Community participation = an active involvement in activities that are intrinsically social and either occur outside the home or are part of a nondomestic role	Up to February/ March 2012	17	No single instrument of the identified 17 instruments was fully satisfactory for measuring community participation. A new measure of community participation with a better design and greater coverage of community participation based on the ICF should be developed.
Eyssen 2011b	To evaluate whether instruments which intend to measure participation actually do so and how frequently specific aspects and domains of participation are addressed.	Generic and condition-specific	Performing roles in the domains of social functioning, family, home, financial, work/education, or in a general domain.	Up to February 2009	68 (measures with ≥50% participation items) IPA included	Most instruments that aim to measure participation do so only to a limited extent. Participation is operationalized differently across instruments. The most frequently used scales of the instruments are participation problems and participation accomplishment. The scale of satisfaction with participation is seldom used. There is a need to achieve consensus on the operationalization of measures of participation, participation domains, and participation aspects.

(continues)

TABLE 1 continues

First author and publication year	Aim of the review	Population	Definition of concept/ focus of measure	Time limits on search	Number of measures included	Conclusions
Magasi 2010	To provide a review of the conceptual foundations, psychometric properties and linkage to the ICF of contemporary participation measures.	Generic	The ICF's definition of participation as "involvement in life situations"	Articles published in 1998- 2008	8 IPA included	Participation instruments that are linked to the same ICF codes may differ in the aspects they represent.
Perenboom 2003	To report which existing survey instruments assess participation according to the ICF.	Generic	The ICF's definition of participation as "involvement in life situations"	Not spesified	11 IPA included	Most instruments evaluated measure one or more domains of the activities and participation list of the ICF, but none of them measure all the domains. Most instruments include also items or response categories other than participation.
Resnik 2009	To compare the content of the measures based on the ICF activities and participation taxonomy and to identify the most comprehensive measures available for use.	Generic and condition-specific	The ICF's definition of participation as "involvement in life situations"	Not specified	40 IPA included	5 measures whose items were linked to all 9 chapters of activities and participation differed considerably in the subcategory of coverage and their approach to assessing participation.

(continues)

TABLE 1 continues

First author and publication year	Aim of the review	Population	Definition of concept/ focus of measure	Time limits on search	Number of measures included	Conclusions
Seekins 2012	To assess the status of methods to measure participation.	Generic and condition-specific	Involving a person fulfilling social roles	From 2001 to March 2009	72, of which 24 cited the ICF	The concept of participation represents more than a ‘‘shift from negative to more positive language.’’ It represents a transformational concept that requires new, dynamic measures collected in context.
Stevelink 2013	To review the cultural equivalence testing process for participation instruments and to provide an overview of the extent to which current insights in cultural equivalence testing have been applied to participation instruments.	Generic	The ICF's definition of participation as "involvement in life situations"	Up to June 2011	8 IPA included	Cultural equivalence has generally not been adequately tested. There is a need to use a cultural equivalence framework when testing the cultural equivalence of a measure.
Van del Velde 2018	To gain an overview of how researchers and clinicians deal with the recurring limitations of the concept of participation and to determine how it is operationalized and how it can be applied.	Generic	The ICF's definition of participation as "involvement in life situations"	Articles published in 1998- 2017	18 IPA included	Experts in the field should combine their knowledge and expertise to find common ground in refining and further operationalizing participation. Agreement on the precise meaning of participation would improve clinical practice.

(continues)

TABLE 1 continues

First author and publication year	Aim of the review	Population	Definition of concept/ focus of measure	Time limits on search	Number of measures included	Conclusions
Focus on measures for a specific population						
Babulal 2015	To identify participation instruments, examine theories/definitions supporting their use and highlight scales for use in low- and middle-income countries for persons with mental illness.	People with several mental illnesses	The ICF's definition of activities and participation and the concept "agency" from capability theory	Articles published in 2003-2014	5	There is a need for participation scales to focus on empowerment as well as collective capabilities. Further, the development of participation scales should clearly delineate the theoretical foundations and concepts used. Finally, participation scales used in low- and middle-income countries should consider how contextual factors like medicine, poverty and disability, particularly with regards to mental illness, impact the content of the scale.

(continues)

TABLE 1 continues

First author and publication year	Aim of the review	Population	Definition of concept/ focus of measure	Time limits on search	Number of measures included	Conclusions
Brandenburg 2015	To evaluate (1) to what extent the included assessments assessed participation only, (2) what content appeared most frequently and (3) which response formats were utilized.	People with aphasia	Three requisites of participation: 1) the summation of a number of activities into a larger societal role or function, 2) accomplished through multiple methods, 3) constitute a socially defined role or have concepts related to a wider social context	Not specified	29 IPA included	Consensus on what constitutes a participation item is required. The content of the instruments fell across many ICF categories, often outside the activities and participation chapter.
Chung 2014	To identify outcome measures in participation used in studies on persons with traumatic brain injury, to examine their relation to the ICF, and to compare their contents with the core sets for traumatic brain injury as references.	People with traumatic brain injury	The ICF's definition of activities and participation: ICF chapters 6,7,8 and 9 describe participation	Articles published between 1992 and December 2012	9	The ICF core sets for traumatic brain injury contain ICF categories for participation in persons with traumatic brain injury that overlapped to varying degrees with all the identified instruments. This is encouraging for both the instruments and the ICF core sets for traumatic brain injury which remain to be validated.

(continues)

TABLE 1 continues

First author and publication year	Aim of the review	Population	Definition of concept/ focus of measure	Time limits on search	Number of measures included	Conclusions
Dalemans 2008	To identify and describe measures of social participation that may be specifically useful when measuring participation in people with aphasia.	People with aphasia	Definition by Whiteneck 'the performance of people in actual activities in social life domains through interaction with others in the context in which they live	Up to 2005	12 IPA included	There is a need to optimize instrument for use in people with aphasia, for example by developing visual and other methods of assistance to support people with aphasia during assessments.
Engel-Yeger 2018	The aim, amongst other aims, was to identify measures of participation used in the stroke literature.	People with stroke	Not specifically defined	Articles published up to April 2017	22 IPA included	Assessments should be used that include a broad perspective on participation domains. However, tools measuring participation must not combine the different aspects of participation into a single overall score.

(continues)

TABLE 1 continues

First author and publication year	Aim of the review	Population	Definition of concept/ focus of measure	Time limits on search	Number of measures included	Conclusions
Mortensson 2008	To identify and to evaluate wheelchair-specific outcome instruments that are useful for measuring activity and participation.	People who use a wheelchair	The ICF's definition of activities and participation	Up to August 2007	11	Most of the identified measures focused on the measurement of wheeled mobility capacity; only 3 instruments looked at activity and participation more broadly. The review found that the psychometric testing of most of these measures was limited.
Noonan 2009	To provide an overview of participation instruments assessed in persons with spinal cord injury and to critically evaluate their measurement properties.	People with spinal cord injury	The ICF's definition of activities and participation: ICF chapters 6,7,8 and 9 describe participation	Articles published in 1980-2008	6 IPA included	The instruments differ in how participation is operationalized. It is important to determine what information about participation is required before selecting an instrument.

(continues)

TABLE 1 continues

First author and publication year	**Aim of the review**	**Population**	**Definition of concept/ focus of measure**	**Time limits on search**	**Number of measures included**	**Conclusions**
Resnik 2017	To conduct a systematic review of community integration measures used with populations with limb trauma, amputation, or both, and to evaluate each measure's focus, content, and psychometric properties.	People with limb trauma or amputation	The ICF's definition of activities and participation; participation comprises complex functional tasks and actions; uses the terms community integration and participation synonymously	Up to March 2016	34	Evidence of the psychometric properties of the measures were conflicting across studies. Eight scales from 5 instruments had the strongest measurement properties. A few measures of community integration have been developed using the ICF framework.
Tse 2013	To identify and critique the measures currently used to assess participation in clinical stroke studies.	People with stroke	The ICF's definition of activities and participation	Articles published in January 2001-April 2012	36 IPA & COPM included	The 5 frequently used participation measures were systematically linked to the ICF Activities and Participation domains. None of the reviewed participation measures fully covered all the ICF domains of Activities and Participation.

(continues)

TABLE 1 continues

First author and publication year	**Aim of the review**	**Population**	**Definition of concept/ focus of measure**	**Time limits on search**	**Number of measures included**	**Conclusions**
Vergauwen 2014	To summarize measurement instruments used to evaluate activity limitations and participation restrictions in patients with chronic fatigue syndrome and review the psychometric properties of these instruments.	People with chronic fatigue syndrome	The ICF's definition of activities and participation	Up to July/ October 2012	38 COPM included	The psychometric properties of the reviewed measures are not sufficiently evaluated.

COPM = Canadian Occupational Performance Measure
ICF = International Classification of Functioning, Disability and Health
IPA = Impact on Participation and Autonomy questionnaire

In the above reviews, participation measures were classified and examined according to their different approaches - static, interactive, or dynamic. In the interactive and dynamic approaches, for example, the evaluation of environmental factors was integrated into the participation measure, and the knowledge gained from the interactive or dynamic measures was deeper than that obtained from static measures (Seekins et al. 2012).

The response formats of the different measures varied, rendering it difficult to compare measures and choose the most appropriate measure. For example, the analysis of the 29 measures which contain more than 50 percent of the participation items and cover more than one ICF chapter of activity and participation showed that the items in the measures were asking about participation restriction, frequency, satisfaction and enjoyment, assistance, importance, custom, difficulty and desire for change in participation (Brandenburg et al. 2015).

Irrespective of the aspect of participation being measured, the measure should be valid and reliable. Frequently, the psychometric properties of the measures have not been well enough tested (Mortenson et al. 2008, Vergauwen et al. 2015, Resnik et al. 2017). The international COnsensus-based Standards for the selection of health status Measurement INstruments (COSMIN) checklist has been developed to guide evaluation of the methodological quality of studies on measurement properties. The checklist items concern evaluation of a measure's validity, reliability, responsiveness, generalizability and interpretability (Mokkink et al. 2010).

2.4.2 Evaluation of subjective participation of people with MS

In chronic and progressive conditions such as MS, it is essential to measure participation from the perspective of the individual concerned. As described earlier in chapter 2.1.2, the symptoms of MS and contextual factors that influence functioning in everyday life activities and participation of persons with MS are dynamic, complex and highly individual. Subjective measures enable a person's experiences of participation to be captured; for example, how satisfied the person is with current participation in everyday life or how important participation in a particular set of activities is for him or her (Brown 2010). In addition, subjective measures may help clinicians to encourage people with MS to share their everyday life stories, which support art of rehabilitation practice (Finlayson 2013). Therefore, subjective measures of activities and participation in everyday life were chosen for this dissertation research.

Self-report measures of activities and participation of people with MS were searched via two MS-specific sources and one source which enables MS-specific search. The first source, the Academy of Neurologic Physical Therapy Outcome Measures Recommendations, gave recommendations for the use of outcome measures in people with multiple sclerosis (Potter et al. 2012). The aim of the recommendations is to help clinicians choose appropriate measures, as the group of people with MS are heterogeneous and their symptoms are diverse (Cohen et al. 2015). A total of 63 measures are reviewed and recommended for use in clinical practice, education and/or research (Potter et al. 2012). Altogether, 17 measures of participation, categorized by the authors under 1. Health and wellness, 2. Home management, 3. Leisure, 4. Quality of life, 5. Role function, 6. Shopping, 7. Social function and 8. Work, are recommended, 16 of which are self-report measures (Table 2). The performance-based observation measure "Functional Independence Measure" was excluded.

The second source, the Rehabilitation Measures Database (Moore et al. 2014), is a resource that clinicians and researchers can use to identify reliable and valid instruments from among the over 400 measures that exist for different patient groups. Searches were conducted to identify measures using population filters, i.e. "multiple sclerosis" AND area of assessment, i.e. "activities of daily living" OR "life participation" OR "occupational performance". In total, 11 measures were identified, eight of which were self-report measures (Table 2). The performance-based observation measures "Functional Independence Measure" and "Executive Functional Performance Test" were excluded as also was the "Functional Behavior Profile", which was a questionnaire for primary caregivers.

The third source, the National MS Society, provides information about the most frequently used measures. Measures are categorized according to the following ICF components: 1) impairments of body functions and body structures, 2) activity limitations and participation restriction, and 3) environmental factors. The search yielded a total of ten instruments for assessing activity and participation, of which nine were self-report measures (Table 2). The Multiple Sclerosis Functional Composite (MSFC), which contains three performance-based observation measures, was excluded.

Altogether, 28 diverse self-report measures were found, five of which were listed in two of the above sources. None of the measures were found in all three sources. Self-reports covering multiple aspects of the life situation yielded a further ten, of which six were quality of life measures, one a health status measure and one an impact of disease measure. The other two measured perceived disability and handicap. Three measures based on individuals' self-initiated everyday activities rated by their difficulty or activities chosen as a goal, the attainment of which was measured. More than half of the measures focused on a specific component of participation such as fatigue or a movement or issues linked to participation such as the impact of environmental factors on participation or cognition, vision, mental health, sexual satisfaction or pain.

In part, the diversity of measures found in this search can be explained by the filters or categorizations used in the data sources. Nevertheless, it can be argued that the variability and multiplicity of the definitions of participation used also influence the diversity of the measures found. According to this search, no single measure is clearly better in some way than others, or the most commonly used, or more strongly recommended than the others.

TABLE 2 Self-report measures of everyday activities and participation for people with MS from three sources

	The Multiple Sclerosis Task Force	**Rehabilitation measures database**			**The National MS Society**
	*	**	***	****	*****
(Health related) Quality of Life					
1. Functional Assessment of MS	x				
2. MS International Quality of Life questionnaire	x				
3. Multiple Sclerosis Quality of Life (MS-QOL 54)	x				x
4. Multiple Sclerosis Quality of Life Inventory	x				
5. Short Form Health Survey of the Medical Outcomes Study (SF–36)	x				x
6. Incontinence Quality of Life Scale		x			
Health Status/ impact of disease					
7. London Handicap Scale (LHS)		x	x	x	
8. Multiple Sclerosis Impact Scale (MSIS–29)	x				
Person's perception of disability and handicap					
9. Dizziness Handicap Inventory	x				
10. Guy's Neurological Disability Scale	x				
Ratings of activities or goals chosen by patients					
11. Canadian Occupational Performance Scale (COPM)	x				
12. Patient-specific Functional Scale	x	x			
13. Goal Attainment Scaling (GAS)	x				
Fatigue					
14. Fatigue Descriptive scale	x	x	x		
15. Multi-component Fatigue Scale	x				
16. Modified Fatigue Impact Scale (MFIS)					x
17. Fatigue Severity Scale		x	x		

(continues)

TABLE 2 continues

	The Multiple Sclerosis Task Force	Rehabilitation measures database		The National MS Society
Movement				
18. Activities-specific Balance Confidence Scale (ABC)	x			
19. A measure of manual ability for adults with upper limb impairment ABILHAND		x		
20. Multiple Sclerosis Spasticity Scale (MSSS–88)	x			
21. Tinetti Falls Efficacy Scale	x	x	x	
Impact of environment factors				
22. Medical Outcome Study (MOS) Modified Social Support Survey (MSSS)				x
23. Quebec User Evaluation of Satisfaction with Assistive Technology		x		
Other dimensions of activity and participation				
24. Impact of Visual Impairment Scale (IVIS)				x
25. Mental Health Inventory (MHI)				x
26. Perceived Deficits Questionnaire (PDQ)				x
27. Sexual Satisfaction Scale (SSS)				x
28. Medical Outcome Study (MOS) Pain Effects Scale (PES)				x

*Search for “Participation” which was defined in the source as “1. Health and wellness, 2. Home management, 3. Leisure, 4. Quality of life, 5. Role function, 6. Shopping, 7. Social function and 8. Work”

**Search for filters “multiple sclerosis” AND “activities of daily living”

***Search for filters “multiple sclerosis” AND “life participation”

****Search for filters “multiple sclerosis” AND “occupational performance”

*****List of the measures of “activity and participation” for people with MS

2.4.3 Measures of self-perceived participation in everyday life in people with MS: Canadian Occupational Performance Measure and Impact on Participation and Autonomy

It has been emphasized that evaluation of participation in people with MS should include participation in a variety of daily activities performed at home, outside home, and during leisure time (Ben Ari Shevil et al. 2014). The finding based on the reviews on measures of participation for different target populations presented in Table 1 supports this view. No single suitable participation measure exists that can applied across all situations or client groups (van de Velde et al. 2018). Thus, there is a need to consider what measure best suits a particular purpose and situation.

A few common features or questions which should be considered when choosing a measure in a particular situation were mentioned. The selection of a measure should be based on the domains, aspects and levels of specificity of participation that are to be measured (Magasi & Post 2010). In addition, it is important to ascertain if the measure is unidimensional, that is, the results of the measure describe participation as a large and complete phenomenon, or multidimensional, that is, yields knowledge about participation from multiple aspects (van de Velde et al. 2018).

In the present research, the primary focus was on everyday activities and participation from the viewpoint of the individual, paying special attention to the aspect of autonomy in participation.

As the search for MS-specific participation measures showed, no single measure was clearly better than the others. Therefore, two generic self-report measures of everyday activities and participation with adequate psychometric properties were chosen: the Canadian Occupational Performance Measure (COPM), which is included in the Multiple Sclerosis Task Force and the Impact on Participation and Autonomy (IPA) questionnaire, which defines participation from the perspective of the sense of autonomy. These measures differ in how they are implemented – the COPM is a semi-structured interview and the IPA is a questionnaire with structured response options. Therefore, they provide complementary information on participation in everyday life. Both have been used previously with people with MS.

Canadian Occupational Performance Measure

The COPM was developed in Canada almost thirty years ago to support the client-centered practice of occupational therapy (Law et al. 1990). The COPM is designed to enable people with disabilities to identify and prioritize everyday activities of self-care, productivity and leisure and to assess how they restrict or impact everyday living (Law et al. 2014). It has been translated into 35 languages and over 400 articles have been published on the psychometrics of COPM or on the use of the COPM as an outcome measure (COPM 2019). It was translated into Finnish in 2011 (Baptiste et al. 2011).

The literature review summarizing the results of 19 articles on the psychometric properties of the COPM suggests that its reliability, validity and responsiveness are all acceptable. The results of three studies indicated strong test-retest reliability for both the performance and satisfaction scores when tested one week apart. Eleven studies of concurrent and content validity supported the COPM as a valid measure. An interesting finding was the relatively low correlation found between the COPM and an objective functional measure (Functional Independence Measure). This result was speculated to be related to the difference between the scores for the same items measured objectively and subjectively. The responsiveness or sensitivity to change of the COPM was supported in five studies (Carswell et al. 2004). Moreover, at least two studies with a sample of persons with different diagnoses, including multiple sclerosis, which were conducted after the review, strengthen the view that the changes observed in the COPM performance and satisfaction scores over time are valid (Dedding et al. 2004, Eyssen et al. 2011a) .

The impact of the COPM on clinical practice was shown in a review of 64 articles. Specially, the COPM seems to reinforce the client-centered model of practice and serve as a tool to guide the partnership between clinician and client. In addition, the COPM focuses on both the functional and quality perspectives of occupational performance (Parker & Sykes 2006). A trend was found indicating that the administration of the COPM improves different dimension of clinical practice, such as knowledge of important client issues and outcomes, clinical decision making for initial and ongoing treatment, and clinician ability to state client outcomes clearly (Colquhoun et al. 2012). However, professional communication skills and power sharing as well as an institutional commitment are needed when implementing the COPM to support client-centered practice (Enemark Larsen et al. 2018).

The COPM has been used as an outcome measure in people with MS in studies on various kinds of adaptive equipment, such as improving functional ability with standing in an Oswestry frame (Hendrie et al. 2015), decreasing upper limb tremor with sensory dynamic orthoses (Miller et al. 2016) and improving activities of daily living with the Odstock dropped foot stimulator (Esnouf et al. 2010). Moreover, the COPM was used as a primary outcome measure in a study which compared an individual self-management occupational therapy intervention program and relaxation for people with MS (Kos et al. 2016). In addition, self-perceived performance and satisfaction with performance of daily activities were assessed on admission to and at discharge from interdisciplinary rehabilitation (Lexell et al. 2014). In a recent Iranian study, the COPM was used to assess which activities were perceived as difficult to perform and their relation to the level of disability (Dehghan et al. 2019).

The Impact on Participation and Autonomy

The IPA was developed in the Netherlands two decades ago to measure perceived participation (Cardol et al. 1999a). The questionnaire addresses the concept of autonomy, which was defined as a pre-requisite for effective participation (Cardol et al. 2002).

The IPA has been translated into several different languages, including English, French, Persian, Swedish, Danish and Thai. Research on the psychometric properties of the IPA have been conducted with the English (Cardol et al. 2002, Sibley et al. 2006a), Swedish (Lund et al. 2007), French (Poulin & Desrosiers 2010), Persian (Fallahpour et al. 2011), Danish (Ghaziani et al. 2013) and Thai versions (Suttiwong et al. 2013). Furthermore, a comparison of the Dutch and English version has been conducted (Kersten et al. 2007). In addition, there are at least two modified versions of the IPA, one for elderly people (IPA-O)(Hammar et al. 2014) and another for people with a need for social support (IPA-MO) (Berenschot & Grift 2019). The IPA was translated into Finnish in 2011 using back-translation and expert-group consensus (Kanelisto & Salminen 2011).

The psychometric properties of the IPA among people with MS were evaluated in at least three studies (Vazirinejad et al. 2003, Sibley et al. 2006, Vazirinejad et al. 2015). The acceptability of the English version of the IPA was evaluated by 35 persons with MS who considered that, of the IPA domains, the Mobility domain was the most relevant and the Education domain the least important (Vazirinejad et al. 2003). The study did not evaluate the construct validity and reliability of the IPA (Vazirinejad et al. 2003). The study which, among people with other diagnoses, included sixty people with MS showed that the English IPA is a valid, reliable and acceptable measure of participation and autonomy in people with a range of conditions (Sibley et al. 2006). In addition, the Persian version of the IPA was considered a valid and reliable instrument for assessing participation among people with MS in Iran (Vazirinejad et al. 2015). Although, the IPA is seen as an appropriate measure for people with MS, the need remains to further measure the psychometric properties of the IPA among Finnish-speaking people with MS.

The IPA was used as an outcome measure at least in five MS studies (Kos et al. 2007, Jongen et al. 2014, Rietberg et al. 2014, Blikman et al. 2017, van den Akker et al. 2017). No significant changes in participation and autonomy were found after cognitive behavioral therapy (van den Akker et al. 2017), energy conservation management (Blikman et al. 2017), multidisciplinary rehabilitation (Rietberg et al. 2014) or a multidisciplinary fatigue management program (Kos et al. 2007). However, social cognitive wellness programs involving support partners showed positive effects on autonomy and participation (Jongen et al. 2014).

Cross-sectional studies have also examined associations between different aspects of IPA-measured functioning and participation in people with MS. These cross-sectional studies found associations of participation and autonomy with walking ability and performance (Ryan et al. 2018) and appraisal, defined as the evaluation of a situation or ability to deal with the situation (van den Akker et al. 2016), aerobic capacity (Driehuis et al. 2018) and also disability and quality of life (Kwiatkowski et al. 2014).

2.4.4 Multidisciplinary rehabilitation

The recent overview of the Cochrane Database Systematic Reviews summarizes the evidence on rehabilitation interventions for people with MS from 15 systematic reviews (Amatya et al. 2019). Fourteen reviews addressed therapies provided by a single discipline such as physiotherapy, occupational therapy, nutritional interventions or psychological interventions. Two reviews of physical therapeutic exercise programs (Rietberg et al. 2005, Heine et al. 2015) and a review of information-provision interventions (Köpke et al. 2014) showed moderate quality evidence. Reviews of hyperbaric oxygen therapy (Bennett & Heard 2004), whole-body vibration (Sitjà Rabert et al. 2012), cognitive and psychological interventions (Thomas et al. 2006, Rosti-Otajärvi & Hämäläinen 2014, das Nair et al. 2016), vocational rehabilitation (Khan et al. 2009), telerehabilitation (Khan et al. 2015), dietary intervention with different form of polyunsaturated fatty acids (Farinotti et al. 2012) and interventions for the management of spasticity (Amatya et al. 2013) showed low-quality evidence. In addition, inconclusive evidence was found for a dietary intervention (D-vitamin) (Jagannath et al. 2010) and occupational therapy strategies (Steultjens et al. 2003).

The overview of reviews (Amatya et al. 2019) included one review of multidisciplinary rehabilitations (9 RCTs and 1 CCT) that were originally conducted in 2007 and updated in 2011 (Khan et al. 2011). Four of the studies were conducted in the USA, two in Italy, two in the UK, one in Denmark and one in Australia. The interventions were diverse. The shortest intervention lasted 3-8 days and the longest one year. Typically, the shorter interventions were inpatient interventions and the longer ones were outpatient or home-based interventions. Physiotherapists, occupational therapists, speech therapists, psychologists, social workers and nurses were the professionals who most commonly conducted the interventions. In addition, there was heterogeneity in patient characteristics, severity of MS, stages of MS, and the measurement tools used. Therefore, instead of a synthesis of the best evidence, qualitative analysis was applied. The review showed that neither inpatient nor outpatient multidisciplinary rehabilitation changes functioning on the ICF level of impairment. However, multidisciplinary rehabilitation may improve activity and participation of people with MS. The evidence was assessed as of moderate quality.

To capture recent articles on multidisciplinary rehabilitation for people with MS, the Medline Ovid search was conducted from 2011 to April 2019 [(multiple sclerosis.mp. OR Multiple Sclerosis/) AND (multiprofessional.mp. OR multidisciplinary.mp. OR Interdisciplinary Research/or interdisciplinary.mp. OR Interdisciplinary Studies/) AND (Neurological Rehabilitation/ OR rehabilitation.mp. OR Rehabilitation/ OR Rehabilitation Research/)]. The search yielded four articles (Table 3). The multidisciplinary rehabilitation conducted in an inpatient setting compared to waiting list controls showed better outcomes in experiences of the psychological impact of the disease and health-related quality of life after four weeks of rehabilitation (Boesen et al. 2018) and in walking speed after three months rehabilitation (Salhofer-Polanyi et al. 2013). The study comparing a one-year integrated and non-integrated multidisciplinary rehabilitation in an outpatient setting showed no difference in results (Papeix et al. 2015). Another study conducted in an outpatient setting compared multidisciplinary rehabilitation to consultation with a nurse and showed no difference in fatigue (Rietberg et al. 2014).

The low number of multidisciplinary rehabilitation studies with heterogeneous study designs targeted to people with MS highlight the need for further studies, although the implementation of a high-quality clinical study for this specific group is challenging. It has been emphasized that the discrepancies between an individual- and empirical-based rehabilitation and an evidence-based, scientific approach may present a problem for clinical studies. This may be caused, for example, by the heterogeneity of people with MS, lack of well-defined control or intervention groups, or the medications used to alleviate symptoms of the disease and difficulties in measuring change (EMSP & R.I.M.S. 2012).

There is a need for research on multidisciplinary rehabilitation from the viewpoint of the effects of the rehabilitation and of the factors that create the effects. Moreover, most the studies evaluated the outcomes of short-term interventions. Therefore, studies on the effectiveness of long-term interventions are needed. A previous review (Khan et al. 2011) and the updated search in this thesis highlight the need to incorporate the perspective of people with MS in the study design and especially, participation of people with MS in daily life need further evaluation.

TABLE 3 Studies identified in the search via Medline

First author, year, country	**Aim of the study**	**Setting (inpatient/ outpatient)**	**Number of participants (n); EDSS score (mean/median, SD, min;max, IQR)**	**Intervention**	**Summary of findings (measurement time)**
Boesen, 2018, Denmark	To evaluate the longer-term effectiveness of inpatient multidisciplinary rehabilitation (MDR) on the health-related quality of life of MS patients	Inpatient	Treatment group: 214 mean 5(3.5;6,.5) control group: 213 mean 4,5(3,.5;6,.5)	Treatment group: inpatient MDR, including consultation, individual and group-based therapy, lessons on different topics, supervised self-directed exercise with input from different disciplines depending on the patient's main focus area. Control group: 6 months on a wait list Duration of treatment: 4 weeks	Treatment group showed better scores than control group in psychological impact of disease (MSIS-29 Psychological) and health related quality of life (15D) (follow-up 6 months)
Papeix, 2015, France	To address the effectiveness of an integrated MDR versus usual MD care on quality of life in MS patients	Outpatient	Treatment group: 25 median 6(2.5;8.5) control group: 25 median 6(3;8)	Treatment group: treatment period consisted of an integrated MDR at the MS clinic with a half-day (four to six hours) individually tailored assessment by the multidisciplinary group at the beginning of treatment period. Then depending on patients' needs, evaluated during the inclusion visit and re-evaluated during the multidisciplinary visit, patients were seen by different MS specialists and allied health professionals. Control group: non-integrated interventions with different specialists and allied health professionals at different times and sites Duration of treatment: 12 months	The integrated MDR approach did not differ from usual MD approach regarding quality of life (MSIS-29) (6 months & 12 months)

continues

TABLE 3 continues

First author, year, country	**Aim of the study**	**Setting (inpatient/ outpatient)**	**Number of participants (n); EDSS score (mean/median, SD, min;max, IQR)**	**Intervention**	**Summary of findings (measurement time)**
Rietberg, 2014, Netherlands	To assess the effects of individually tailored, outpatient MDR on chronic fatigue	Outpatient	Treatment group: 23 median 3, IQR 3 control group: 25 4, IQR 2	Treatment group: an individually tailored program that focused on optimizing self-management behavior in daily life activities and energy conservation conducted by a physical therapist or occupational therapist or social worker or any combination of these specialists. Control group: nurse consultation (NC) Duration of treatment: 12 weeks	No differences were found between MDR or NC in fatigue (post-intervention 3 months & follow-up 6 months)
Salhofer-Polanyi, 2013, Austria	To evaluate the benefit of inpatient MDR on walking speed	Inpatient	Treatment group: 10 median 6(4;6.5) control group: 9 median 5.5 (4;6.5)	Treatment group: Inpatient MDR Control group: waiting list group Duration of treatment: 3 months	Treatment group showed better scores than control group in walking speed (Timed 50 meter walk, walking speed, 6-minute walk) (3 months)

EDSS = Expanded Disability Status Scale
MDR = Multidisciplinary rehabilitation
NC = Nurse consultation
MSIS-29 = The Multiple Sclerosis Impact Scale
IQR = Interquartile range

In summary, according to the literature review, to be able to support the participation in everyday life of persons with MS in the best possible way calls for research on their everyday life. MS is a progressive and unpredictable disease that causes patients multifaceted challenges in participation in everyday life. Therefore, a person-centered and a multidisciplinary approach is needed to better achieve the primary goal of MS rehabilitation, which is to enhance MS patients' participation in daily life.

ICF offers a holistic framework for multidisciplinary clinicians to evaluate functioning, set goals, plan interventions, and communicate. The ICF core sets for MS are practical tools that cover multiple symptoms and limitations in the functioning of people with MS in their physical, social, and attitudinal environment. However, there is a need to further investigate the validity of the ICF core sets from the viewpoint of people with MS.

Participation has been recognized as a complex phenomenon and hence many other definitions of participation exist in addition to that of the ICF. Owing to the need to better understand the participation of people with MS and to investigate contextual factors and their links to participation, especially from the point of view of MS individuals themselves, subjective measures are required.

The search identified 28 diverse subjective measures of the activities and participation of people with MS. According to the search, no single measure was clearly better, or more commonly used, or more strongly recommended than any other. As the primary focus of the present research was on everyday activities and participation from the viewpoint of the individual, with special attention to the aspect of autonomy in participation, two generic self-report measures of everyday activities and participation that had demonstrated adequate psychometric properties were chosen: the COPM, which enables people with MS to identify and prioritize their everyday activities of self-care, productivity and leisure and to assess how they performe them and the IPA questionnaire, which defines participation from the perspective of the sense of autonomy.

The low number of multidisciplinary rehabilitation studies with heterogeneous study designs targeted to people with MS highlight the need for further studies. Particularly needed are studies on the effectiveness of long-term interventions that incorporate the perspective of people with MS in the study design.

3 AIMS OF THE STUDY

The main purpose of this dissertation was twofold: first, to explore the participation and perceived functioning of moderately and severely disabled people with MS in everyday life, and second, to investigate the effect of a two-year multidisciplinary rehabilitation on everyday activities.

The specific aims of this thesis were:

1. To evaluate the psychometric properties of the Finnish version of the Impact on Participation and Autonomy questionnaire for people with MS

2. To explore problems in participation in everyday life as perceived by people with MS and contribute evidence on the validity of the activities and participation categories of the ICF core sets for MS

3. To investigate predictors of participation and autonomy in people with MS

4. To compare changes in the daily activities of moderately and severely disabled people with MS during a two-year, group-based rehabilitation, and to describe how the participants themselves explain these changes

Some previously unpublished results are also included in the dissertation.

4 METHODS

4.1 Study design and participants

This dissertation study applied a multimethod design incorporating both quantitative and qualitative data and analytical methods (Creswell & Plano Clark 2018). The four studies that comprise the dissertation are based on two data set. The first data set is based on data gathered for a multi-professional, group-based out-patient rehabilitation project for people with MS (Group rehabilitation project data set) conducted in 2010-2012 by the Finnish NeuroSociety together with the Finnish Social Insurance Institution and the GeroCenter Foundation for Aging Research and Development. Group rehabilitation project data set was applied in all four studies. In addition, for studies I and III, data were collected from people with MS in 2012–2013 during an inpatient rehabilitation period of 1–3 weeks at Masku Neurological Rehabilitation Center (IPA data set) (Table 4).

TABLE 4 Summary of the designs, participants and outcomes of the four studies

Study	Data set	Study design	Participants (n)	Age range, years	Main outcome measures
I	Group rehabilitation project (intervention & comparison groups) + IPA	cross-sectional study	194	26-65	Impact on Participation and Autonomy (IPA)
II	Group rehabilitation project (intervention & comparison groups)	cross-sectional study	113	28-61	Canadian Occupational Performance Measure (COPM)
III	Group rehabilitation project (intervention & comparison groups) + IPA	cross-sectional study	194	26-65	Impact on Participation and Autonomy (IPA) WHO Quality of Life BREF (WHOQOL-BREF) Multiple Sclerosis Impact Scale-29 (MSIS-29) Expanded Disability Status Scale (EDSS)
IV	Group rehabilitation project (intervention group)	prospective cohort with 21-month follow-up	79	28-61	Canadian Occupational Performance Measure (COPM)

4.1.1 Group rehabilitation project data

The group rehabilitation project data set comprised data on 113 participants who attended a two-year multi-professional, out-patient rehabilitation project for people with MS. In study II, the data consisted of Canadian Occupational Performance Measure assessments at the first time-point, i.e. before the beginning of the rehabilitation program. Of the original 113 participants, 90 entered the group rehabilitation intervention, three withdrew before the intervention started and 20 were assigned to a comparison group which received usual care. The most common rehabilitation procedures used with the comparison group were individual physiotherapy and a 1-3 week period of in-patient multidisciplinary rehabilitation based on individual needs. These procedures did not focus specifically on the four themes of the group rehabilitation intervention. (study II).

In total, 79 participants attended the group rehabilitation assessments at all three time-points (at the beginning of rehabilitation, after 12 months and after 21 months) (study IV). Professionals from the Finnish MS Society together with health care professionals recruited the study participants from three areas of Finland: Helsinki, Turku and Northern Savolax. Researchers at the GeroCenter Foundation for Aging Research and Development recruited the comparison MS group from the Jyväskylä and Lahti regions. The inclusion criteria were as follows: (i) age between 18 and 62 (inclusive) years, (ii) a confirmed diagnosis of MS, (iii) restrictions on functioning in at least two of the following four domains: cognition, mood, fatigue and body control. People were excluded, if one or more of the following criteria were met: (i) a Mini Mental State Examination (MMSE) score of below 20/30 (severe cognitive decline) (Folstein et al. 1975) , (ii) a Beck Depression Inventory II (BDI-II) score of over 40/63 (severe depression) (Beck et al. 1961), (iii) an Expanded Disability Status Scale (EDSS) score of under 4.0 or over 8.5 (Kurtzke 1983) or (iv) any other medical or mental condition precluding participation.

The study IV flow chart is presented in Figure 4. The rehabilitation began with 90 participants with MS comprising 42 people with moderate disability and 48 with severe disability. Both those with moderate and those with severe disability took part in the multidisciplinary rehabilitation in groups of 6-8 persons. Each group contained both moderate and severely disabled persons. The flow chart is based on the grouping of participants according to level of disability. Four people with severe disability and seven people with moderate disability withdrew before the baseline measurements. Thus, 79 people were assessed at baseline (T0), after 12 months of rehabilitation (T1) and after 21 months of rehabilitation (T2). In addition, during the T2 assessment, participants were interviewed and asked to name the main reasons for their improving, stable or declining performance in each activity of everyday living identified by the COPM. The assessors followed a common assessment protocol manual and they were not involved in the delivery of the rehabilitation program.

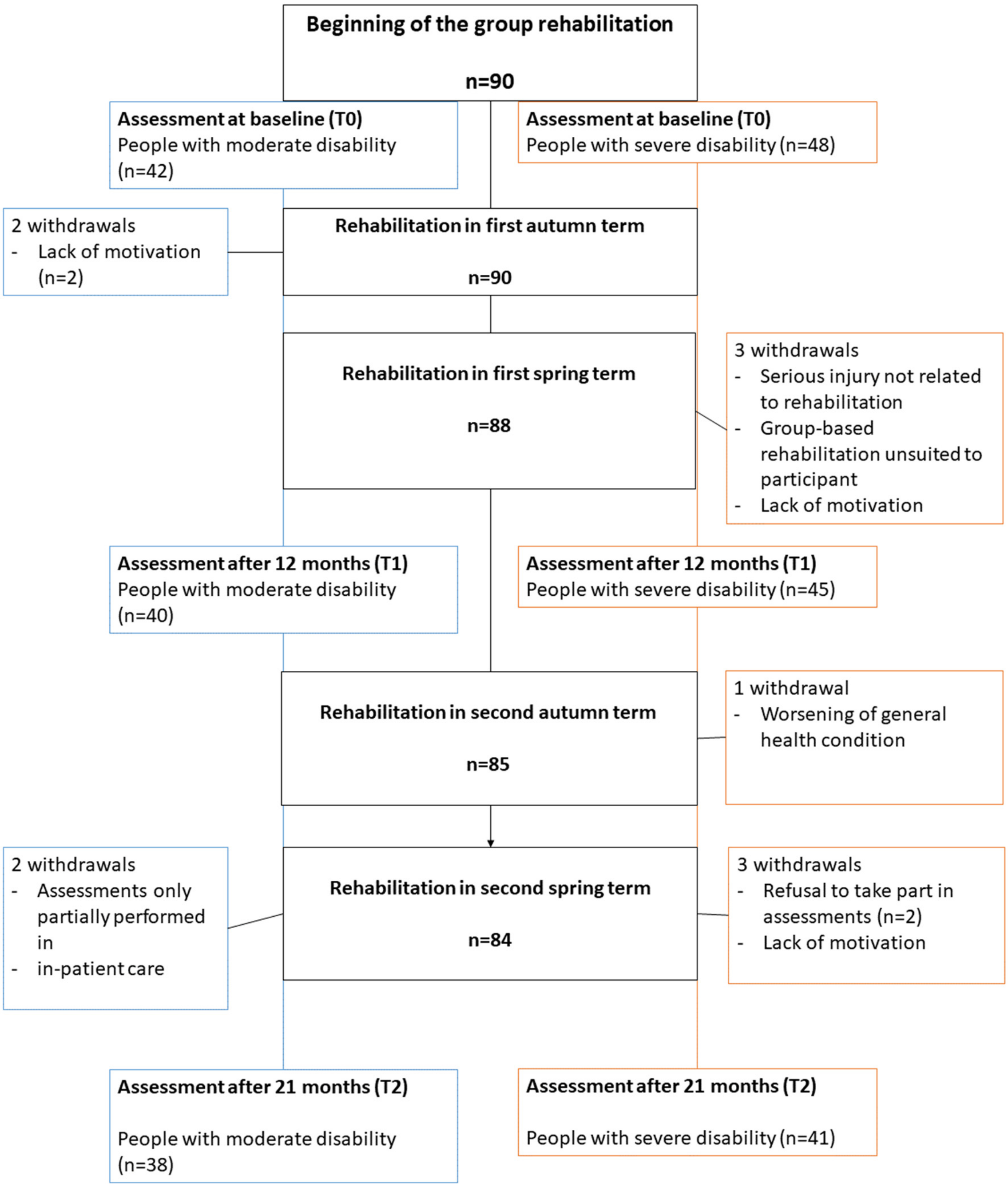


FIGURE 4 The flow chart of the study IV.

4.1.2 IPA data

In addition to the IPA self-reports of 105 participants included in the group rehabilitation project data set, new IPA data (N=89) were collected to evaluate the psychometric properties of the Finnish version of the Impact on Participation and Autonomy questionnaire (IPA) and to study predictors of participation (studies I and III). The IPA data were gathered by professionals during an inpatient rehabilitation period of 1–3 weeks at Masku Neurological Rehabilitation Center in 2012-2013. The inclusion criteria were as follows: (i) age between 18 and 65 years (inclusive), (ii) a confirmed diagnosis of MS, and (iii) the ability to fill in questionnaires independently or with the help of an assistant. People not capable of expressing their own choices or answering questions in the questionnaires were excluded.

4.2 Measurement

Socio-demographic data, including gender, age, housing and employment status, along with disease characteristics, including disease duration, were collected by researchers from the Finnish MS Society (Group rehabilitation data) and professionals from the Masku Neurological Rehabilitation Center (IPA data). In addition, in study II, the Barthel Index was administered by researchers from the Finnish MS Society. The measurements used in the studies are shown in Table 5. Disease course and severity of MS were evaluated by a neurologist using the EDSS. The participants filled in the following questionnaires: the IPA, the WHOQOL-BREF and the MSIS-29. The COPM interviews were conducted by four occupational therapists with a literal protocol for assessment.

TABLE 5 Measurements used in the studies and the focus of the measurements

Measurement	**Study I**	**Study II**	**Study III**	**Study IV**	**Focus of the measurement**
Expanded Disability Status Scale (EDSS)	x	x	x	x	Disease severity
Canadian Occupational Performance Measure (COPM)		x		x	Performance and satisfaction with daily activities (occupations)
Impact on Participation and Autonomy (IPA)	x		x		Participation and autonomy
WHO Quality of Life BREF (WHOQOL-BREF)			x		Quality of life
Multiple Sclerosis Impact Scale 29 (MSIS-29)			x		Psychological and physical impact of disease

4.2.1 Disease severity

The Expanded Disability Status Scale (EDSS) (Kurtzke 1983) was used to evaluate participants' disease severity. The scale was scored by a qualified neurologist. The EDSS score ranges in increments of 0.5 from 0 (no impairment) to 10 (death). The lower EDSS grades (0–3.5) are defined by specific signs in a neurological examination, while grades 4.0 and above are largely dependent on ambulation and use of the upper extremities (Kurtzke 1983).

4.2.2 Daily activities

The Canadian Occupational Performance Measure (COPM) is a measure of outcomes in the areas of self-care, productivity and leisure. It is designed for use by occupational therapists (Law et al. 2005). During a semi-structured interview, participants describe the activities that they want, need or are expected to perform. First, participants, together with an occupational therapist, identify the activities of daily living they perceive as difficult to perform. Participants then rate the importance of each identified activity on a 10-point rating scale (1=not important at all and 10 = extremely important). Finally, participants rate their performance and satisfaction for 1-5 of their most important activities on a 10-point scale (1 = not able to do it at all/ not satisfied at all and 10 = able to do it extremely well/ extremely satisfied).

4.2.3 Participation and autonomy

The Impact on Participation and Autonomy (IPA) questionnaire measures participation from the standpoint of autonomy. The individual answers 41 questions, of which 32 concern perceived participation and autonomy and nine the personal burden of the perceived restrictions on participation. The perceived participation and autonomy aspects comprise the domains of autonomy indoors (7 items), family role (7 items), autonomy outdoors (5 items), social life and relationships (7 items) and work and education opportunities (6 items) (Sibley et al. 2006a.) The nine questions on the personal burden of the perceived restrictions on participation in everyday life form the perceived burden scale, the individual questions providing important information, for example, for rehabilitation goal setting (Cardol et al. 2001).

In the IPA, individuals rate their perceived participation and autonomy for each item on a 5-point Likert-scale ranging from 0 (very good) to 4 (very poor). A standardized mean score is calculated for each domain. Respondents also rate the personal burden of perceived participation restrictions on nine subscales on a 3-point scale from 0 (no problem) to 2 (severe problems). Higher scores indicate a lower sense of autonomy and more perceived participation restrictions (Cardol et al. 2001).

4.2.4 Quality of life

The WHO Quality of Life-Bref (WHOQOL-BREF) (WHOQOL Group, 1998) questionnaire comprises 26 items which assess the following four domains: physical health, psychological health, social relationships, and the environment. Domain scores are calculated by multiplying the mean of all the items included in each domain by four and converting raw scores to transformed scores. Higher scores indicate better perceived quality of life. Thus, each domain score will range from 4 to 20. The psychometric properties, including validity and reliability, have been reported to range from good to excellent (Skevington et al. 2004).

4.2.5 Impact of the disease

The physical and psychological impact of MS was measured using the Multiple Sclerosis Impact Scale (MSIS-29) (Hobart et al. 2001). The questionnaire consists of two subscales: physical (20 items) and psychological (9 items). The sum scores of the physical and psychological subscales can be transformed into percentages. High scores indicate that the disease has a high perceived impact on daily life. The validity and reliability of the subscales have been reported to be good (Hobart et al. 2001).

4.3 Two-year multidisciplinary group intervention (IV)

The multidisciplinary group rehabilitation program lasted 21 months. The program consisted of theme-based group sessions for rehabilitees and their caregivers in out-patient clinics, home visits and networking with other rehabilitation service providers.

The themes of the rehabilitation program covered commonly in the literature reported factors restricting participation in people with MS: cognition, mood, energy conservation and body control. The program was constructed using current research knowledge on interventions addressing these themes and the experiences of professionals. Two versions of each theme were provided: a short version consisting of five three-hour sessions and one whole-day session (one semester) and a long version consisting of 10 three-hour sessions and two whole-day sessions (two semesters). Participants attended sessions on two to four themes, chosen based on their needs and own goals. For each participant, the two-year rehabilitation consisted of 20 half-day sessions and four whole-day sessions. Thus, five half-day sessions and one-whole day session were held each semester. Caregivers had the possibility to participate in one half-day and one whole-day session each semester, and thus altogether in four half-day sessions and four whole-day sessions during the 21-month rehabilitation program. The themed sessions were conducted in groups of four to six persons. The rehabilitation program also included three to five individual home visits focusing on individual need-based assessments of functioning, goal setting and guidance. Two rehabilitation professionals from different disciplines (physiotherapist, psychologist, neuropsychologist, occupational therapist, nurse, social worker) were responsible for guiding the theme groups.

4.4 Study approval and ethics

This study was approved by the Ethics Committee of the Finnish Social Insurance Institution (I, II, III, IV) and the Research Ethics Committee of the Hospital District of Southwest Finland (I, III and additional data). The study was registered in the ISRCTN registry (ISRCTN72556817). All participants gave their written informed consent in accordance with the Declaration of Helsinki 1996. In all phases of the research, privacy and data protection were ensured. All published results are presented without any personal data that could enable identification of individual participants.

4.5 Data analysis

The data analysis was conducted using a both quantitative and qualitative methods. The quantitative data analyses of studies I and III were conducted using Mplus version 6.12. (Muthén & Muthén 2010). The quantitative data analyses of studies II and IV and the additional IPA material were conducted using SPSS 20.0/22.0 for Windows (IBM SPSS Inc.). Theory-driven content analysis was applied to the qualitative data of studies II and IV (Krippendorff 2012).

4.5.1 Structural equation modelling (SEM)

Structural equation modelling (SEM) using Mplus 6.12. was applied in studies I and III. In study I, the multidimensionality of the theoretical construct of participation restrictions of the Finnish version of the IPA was confirmed with confirmatory factor analysis (CFA), which can be viewed as a subset of SEM. In study III, SEM was applied to test a model in which several factors were hypothesized as predictors of participation and autonomy.

SEM includes model specification, identification, estimation, testing fit, and re-specification (Kelloway 2014, Kline 2015). In both studies, the IPA work and educational opportunities domain (6 items) was excluded from the analysis as the items were only applicable to 51 persons.

SEM is premised on two statistical assumptions, namely independence of observations and multiple normally distributed data. The first assumption was met but some correction was needed to satisfy the second assumption. Owing to the non-normal distribution of the data (tested with the Kolmogorov-Smirnov test), both the correlation analysis and SEM were estimated using the full information maximum likelihood method with scale-corrected chi-square test values and robust standard errors (MLR estimate in Mplus 6.12). The few missing values (0-3.6 %) in the data were considered to be missing at random (MAR) and the method for estimation was the full information maximum likelihood method (FIML) (Kelloway 2014).

In study I, analysis of the multidimensionality of the Finnish version of the IPA was conducted in three phases, including testing the original four-factor model, the modified model, and the models for women and men. In the first phase of the analysis, the structural equation model for CFA was specified as a four-factor model comprising 26 items in four domains (autonomy indoors, family role, autonomy outdoors and social relationships) of the IPAFin. In study III, the first phase of the analysis was the estimation of mutual relationships between variables and estimation of the factor model. After this, the identification of the model was examined. Basically, the model should be over-identified, in other words, the number of estimable parameters should be less than the number of variances and covariances of the observed variables (Byrne 2013). In addition, each factor should contain at least three items (Kelloway 2014). Re-specifications needed for the original model were done with the help of standardized residuals, which provide information on the associations of the variables or factors, and modification indices, which provide information about structure in cases of multiple variables.

In study I and III, the fit of the models was tested using chi-square and several goodness-of-fit indices. The goodness-of-fit indices yielded information on absolute fit, fit adjusting for model parsimony, and fit relative to a null model (Brown 2006). Considering and reporting each of these fit indices is recommended, as they provide different information on model fit (Bollen & Long 1993). A statistically non-significant ($p>0.05$) chi-squared statistic means that the model does not significantly differ from the data. The standardized root mean square residual (SRMR) is the average discrepancy between the correlations observed in the input matrix and the correlations predicted by the model (Brown 2006). SRMR values indicating good fit are close to 0.08 or below (Hu & Bentler 1999). The root mean square error of approximation (RMSEA) was used to assess the extent to which a model fits the population reasonably well (Brown 2006). The values of RMSEA show good fit when they are close to 0.06 or below (Hu & Bentler 1999). Comparative fit index (CFI) and Tucker-Lewis index (TLI) values close to 0.95 or above indicate reasonable model fit (Hu & Bentler 1999). In addition, normalized residuals are expected to distribute normally, and absolute values above 2 should not account for more than 5% of all values.

In study I, although there were fewer men than women, the equality of the factor loadings and intercepts was tested. A model where the loadings were fixed equal and a model where the loading was estimated freely were compared with chi-square difference testing using the Satorra-Bentler scaled chi-square (Satorra & Bentler 2001). If the loadings were equal, the analysis was continued and compared to the model where intercepts were also constrained equal and compared to the model in which only factor loadings were fixed equal (Brown 2006).

The internal consistency of each domain of the Finnish version of the IPA was considered good if the Cronbach's alphas were greater than 0.8 (95% CI 0.7-0.9) (Streiner et al. 2014).

4.5.2 Mixed analysis of variance

In study IV, a mixed analysis of variance (ANOVA) (also known as the repeated-measures ANOVA, RM-ANOVA, with a between-subjects factor) was applied to compare changes at three time points (T0, T1 and T2) in the performance and satisfaction with activities of daily life between the moderately and severely disabled groups of people with MS. First, the main assumptions of the data were assessed. The normal distribution of the data was confirmed by boxplot and the

Shapiro-Wilk test (p>0.05 with no outliers in either the scatter plots or box plots. Moreover, the assumption of sphericity was tested using Mauchly's test of sphericity. A mixed ANOVA was then conducted to examine possible interaction effects between the moderate and severe disability groups (between-subjects factor) and time (the within-subjects factor, consisting of the three time points) on performance and satisfaction with activities of daily life. If there was no interaction effect, follow-up tests were performed to determine whether there were any main effects for either of the factors (i.e., groups or time). The post hoc pairwise comparisons tests were performed with Bonferroni corrections (Laerd Statistics 2015).

4.5.3 Theory-driven content analysis

Theory-driven content analysis was applied to the qualitative data of studies II and IV (Krippendorff 2013). In study II, the most important problems (1-5 problems per participant) identified via the COPM were linked to the corresponding ICF categories based on established rules (Cieza et al. 2002, Cieza et al. 2005) to confirm a systematic and standardized linking process. The linking and consensus rules were confirmed by the researchers before the linking process. Each perceived problem was coded to one ICF category according to the meaning of the perceived problem. For example, if the activity 'moving around and enjoying nature' was experienced by the participant as a leisure activity, it was linked to ICF chapter d9 community, social and civic life, and not to ICF chapter d4 mobility. Likewise, the occasion or context pertaining to the problematic activity was considered when linking the activity to an ICF category. In cases of uncertainty, the meaning of the activity for the participant was confirmed from the researcher who interviewed the participant. In addition, researchers documented activities which needed to be considered more closely and the reason for so doing. First, one researcher linked problems to the ICF second-level categories. Another researcher then agreed or disagreed with the choices. Points of disagreement were discussed until a consensus was reached. A third researcher was available for consultation in situations where consensus could not be reached.

In study IV, the interviews on the reasons for change were tape-recorded. The main reasons given for changes in performance in each activity were summarized from the recorded data and transcribed. The meaning unit, which was a person's explanation for a change, was condensed into plain language and filled in an Excel table. They were then assigned to ICF classification categories. For example, a person named "carrying objects" as a problem in everyday life and explained a change in this problem in the words, "although my condition is now worse than before and I can't use a walker, I can carry objects better because I now use a wheelchair. I am also satisfied because I can carry objects by myself". This meaning unit was condensed to "doing daily tasks in a new way". In this case, the condensed meaning unit was coded under the ICF classification personal factors. Theory-driven content analysis was continued with both study

II and study IV data by calculating the frequencies and percentiles of perceived problems (study II) and reasons for change (study IV) coded in each ICF category.

5 RESULTS

5.1 Characteristics of the participants

Background characteristics of participants in each sub-study are summarized in Table 6. Most of the participants in all four studies were severely disabled persons as measured with EDSS and were on a disability pension. Over two-thirds of the participants in all the study groups were women. As expected, the study groups in all studies differed in the proportions of people with different MS disease sub-types. However, in study IV, in which people with moderate and severe disability were compared, no differences were observed in age, disease duration, gender, proportion of people living alone or employment status.

TABLE 6 Summary of participant characteristics in the data sets used in the four studies

	Studies I and III & additional data (n=194)				Study II (n=113)			Study IV (n=79)		
	mild (EDSS 0-3.5; n=8)	moderate (EDSS 4-5.5; n=62)	severe (EDSS 6-9; n=124)	between-group differences p-value	moderate (EDSS 4-5.5; n=43)	severe (EDSS 6-8.5; n=70)	between-group differences p-value	moderate (EDSS 4-5.5; n=38)	severe (EDSS 6-8.5; n=41)	between-group differences p-value
Age, years, mean (SD)	46 (10)	48 (9)	52 (8)	p<0.05[4] moderate-severe p<0.05	47 (9)	49 (8)	ns[1]	48 (9)	48 (9)	ns[1]
Duration of disease, years, mean (SD)	6 (8)	12 (7)	16 (8)	p<0.05[4] mild- severe p<0.05, moderate-severe p<0.05	10 (7)	14 (8)	p<0.05[1]	10 (7)	13 (7)	ns[1]
Female, n (%)	7 (88)	43 (69)	89 (72)	ns[2]	32 (74)	47 (67)	ns[2]	28 (74)	26 (63)	ns[2]
Living alone, n (%)	1 (13)	14 (23)	48 (39)	p<0.05[3]	9 (21)	28 (40)	p<0.05[2]	8 (21)	14 (34)	ns[2]
Employment status, n (%)										
Disability pension	1 (12)	48 (77)	112 (90)	p<0.05[3]	29 (67)	61 (87)	p<0.05[3]	25 (66)	32 (78)	ns[2]
Working	5 (63)	6 (10)	6 (5)		6 (14)	5 (7)		6 (16)	5 (12)	
Student, unemployed, sick-leave or other	2 (25)	8 (13)	6 (5)		8 (19)	4 (6)		7 (18)	4 (10)	
Disease subtype, n (%)										
Relapsing-remitting	7 (88)	34 (55)	23 (19)	p<0.05[3]	23 (53)	22 (31)	p<0.05[2]	21 (55)	12 (29)	p<0.05[2]
Primary-progressive	1 (12)	14 (23)	25 (20)		12 (28)	16 (23)		10 (26)	11 (26)	
Secondary-progressive	0 (0)	14 (23)	73 (59)		8 (19)	29 (41)		7 (19)	16 (39)	
Unknown	0 (0)		3 (2)		0 (0)	3 (4)				

[1] analyzed with t-test, [2] analyzed with chi-squared test, [3] analyzed with Fisher exact test, [4]analyzed with analysis of variance (ANOVA) and pairwise comparisons with Bonferroni test, ns=statistically non-significant

5.2 Transcultural adaptation and validity of IPA (I)

The IPA was translated into Finnish as a part of the group rehabilitation project for moderately to severely disabled people with MS (Kanelisto & Salminen 2011).

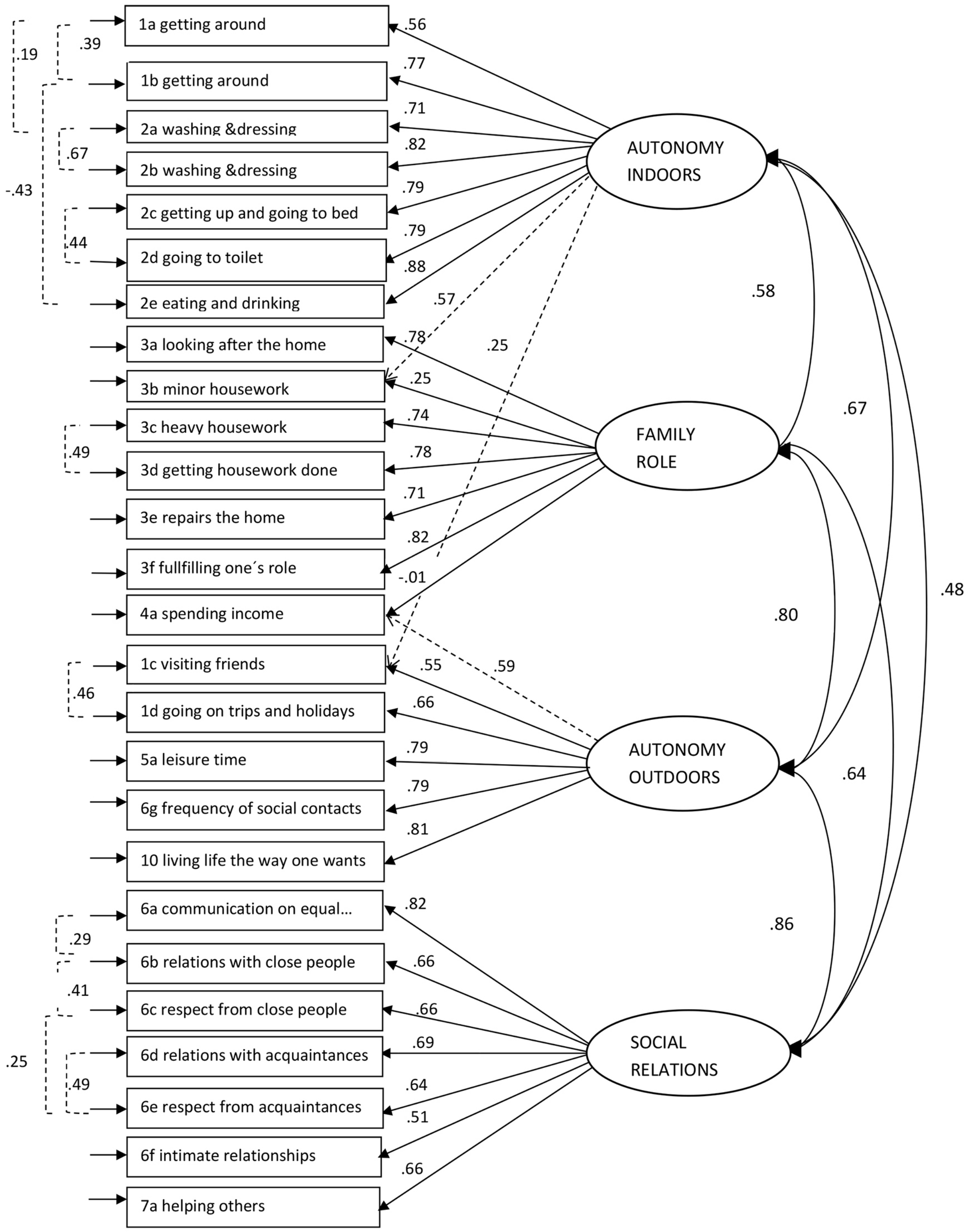
Construct validity

The CFA model without modification (M1) showed poor fit to the data, χ^2(293, N=194) =858,98, $p<0.001$, CFI=0.80, TLI=0.79, RMSEA=0.10, SRMR=0.08. Therefore, the model was modified according to the modification indices of Mplus 6.12. The structure of the modified IPA in the four-factor solution, factor loadings and modifications are presented in Figure 5. The theoretically relevant modifications were as follows: item 3b minor housework in the family role domain and item 1c visiting friends in the autonomy outdoors domain were loaded on the autonomy indoors domain, item 4a spending income in the family role domain was loaded on the autonomy outdoors domain. Furthermore, 11 residual covariance of items within domains were added (presented in Figure 5).

The modified model fitted the data well according to all the indices except chi-square (χ^2(279, N=194)=467,28, $p<0.001$, CFI=0.93, TLI=0.93, RMSEA=0.06, SRMR=0.06). Moreover, normalized residuals were distributed as expected. Correlations between the factors were quite high, ranging from 0.48 (autonomy indoors and social relationships) to 0.86 (autonomy outdoors and social relationships). The equality of the factor loadings and intercepts of the model between women and men was confirmed (Table 7).

Reliability

The internal consistency of all domains was high, as determined by Cronbach's alpha: 0.91 (autonomy indoors), 0.88 (family role), 0.88 (autonomy outdoors) and 0.85 (social relationships). Cronbach's alpha for the IPA domain work and education, which was measured with a smaller sample (n=51), was 0.80.



arrow with dashed line = modifications

FIGURE 5 Confirmatory factor model for the modified IPA four factor solution.

TABLE 7 Measurement invariance of the IPA in men and women with MS tested with three different models and model comparisons

Model	χ^2	df	χ^2_{diff}	Δdf	p-value	CFI	TLI	RMSEA	SRMR
M1= Freely estimated factor loadings	912.44	558	-	-	-	0.90	0.88	0.08	0.07
M2 = Equal factor loadings	922.40	580	16.17	22	0.81	0.90	0.89	0.08	0.08
M3= Equal indicator intercepts	951.36	601	28.79	21	0.12	0.90	0.89	0.08	0.08

χ^2 = Chi-squared statistic, df = Degrees of freedom, χ^2diff = Chi-squared difference test, Δdf = the difference of degrees of freedom, p-value = p-value of chi-squared difference test, CFI = Comparative fit index, TLI = Tucker-Lewis index, RMSEA = Root mean square error of approximation, SRMR = Standardized root mean square residual

5.3 Challenges in self-perceived participation in everyday life of people with MS (II + additional material)

Challenges in participation in everyday life were evaluated using two different kinds of self-assessment measures. The COPM is a semi-structured interview method in which individuals identify and name the activities they experience as challenging in everyday life. The IPA, in contrast, is a structured questionnaire in which the activities and areas of participation to be self-assessed from the perspective of autonomy have been defined beforehand.

5.3.1 Problems in everyday activities measured with the COPM

In the COPM interview, the participants identified 527 most important problems. These problems covered all nine ICF activity and participation domains (Table 8). The number of most important problems identified per participant varied from one to five. The participants with moderate disability most frequently perceived problems in activities linked to the ICF domains d4 mobility (29,3%) and, second most frequently, d9 community, social and civic life (25,5%). In turn, the participants with severe disability most frequently perceived problems in activities linked to the ICF domains d9 community, social and civic life (29,2%) and, second most frequently, d4 mobility (22,9%). Both participants with moderate and severe disability also frequently perceived problems in activities linked to the following domains: d5 self-care (15,9% and 16,0%) and d6 domestic life (17,8% and 19,0%).

No statistically significant differences were observed in the most important problems in the ICF activity and participation first-level domains reported by those with moderate and those with severe disability. However, the analysis of the ICF activity and participation third-level categories revealed statistically significant differences between the groups in their assessments of two categories: 1) d450 walking and 2) d640 doing housework. People with moderate disability more often reported problems in walking than those with severe disability, whereas people with severe disability reported more problems in doing housework than those with moderate disability.

TABLE 8 The most important problems (n=527) in the ICF activities and participation categories reported by participants with moderate (n=43) and severe disability (n=70) in COPM

ICF Code	Category title	Problems identified by people with moderate disability n (%)	Problems identified by people with severe disability n (%)	Total n (%)
Domain 1: Learning and applying knowledge		5 (2,4)	4 (1,3)	9 (1,7)
d155	Acquiring skills[1]	1 (0,5)	1 (0,3)	2 (0,4)
d166	Reading[1]	2 (1,0)	1 (0,3)	3 (0,6)
d170	Writing[1]	2 (1,0)	2 (0,6)	4 (0,8)
Domain 2: General tasks and demands		8 (3,8)	13 (4,1)	21 (4,0)
d210	Undertaking a single task[1]	3 (1,4)	3 (0,9)	6 (1,1)
d230	Carrying out daily routines[1, 2]	4 (1,9)	10 (3,1)	14 (2,7)
d240	Handling stress and other psychological demands[1]	1 (0,5)	0 (0)	1 (0,2)
Domain 3: Communication		3 (1,4)	0 (0)	3 (0,6)
d350	Conversation[1]	3 (1,4)	0 (0)	3 (0,6)
Domain 4: Mobility		61 (29,3)	73 (22,9)	134 (25,4)
d410	Changing basic body position[1]	3 (1,4)	4 (1,3)	7 (1,3)
d415	Maintaining a body position[1]	2 (1,0)	3 (0,9)	5 (0,9)
d420	Transferring oneself[1]	0 (0)	5 (1,6)	5 (0,9)
d430	Lifting and carrying objects[1]	6 (2,9)	13 (4,1)	19 (3,6)
d440	Fine hand use[1]	1 (0,5)	1 (0,3)	2 (0,4)
d445	Hand and arm use[1]	4 (1,9)	3 (0,9)	7 (1,3)
d450	**Walking**[1,2, χ]	15 (7,2)	8 (2,5)	**23 (4,4)**
d455	Moving around[1]	6 (2,9)	7 (2,2)	13 (2,5)
d460	**Moving around in different locations**[1]	18 (8,7)	18 (5,6)	**36 (6,8)**
d465	Moving around using equipments[1]	0 (0)	5 (1,6)	5 (0,9)
d470	Using transports[1]	2 (1,0)	4 (1,3)	6 (1,1)
d475	Driving[1]	4 (1,9)	2 (0,6)	6 (1,1)

(continues)

TABLE 8 continues

ICF Code	Category title	Problems identified by people with moderate disability n (%)	Problems identified by people with severe disability n (%)	Total n (%)
Domain 5: Self-care		33 (15,9)	51 (16,0)	84 (16,0)
d510	**Washing oneself**[1]	9 (4,3)	19 (6,0)	**28 (5,3)**
d520	Caring for body parts[1]	10 (4,8)	9 (2,8)	19 (3,6)
d530	Toileting[1]	1 (0,5)	6 (1,9)	7 (0,4)
d540	**Dressing**[1]	7 (3,4)	16 (5,0)	**23 (4,4)**
d550	Eating[1]	5 (2,4)	0 (0)	5 (0,9)
d570	Looking after one's health[1]	1 (0,5)	1 (0,3)	2 (0,4)
Domain 6: Domestic life		37 (17,8)	61 (19,1)	98 (18,6)
d620	**Acquisition of goods and services**[1]	10 (4,8)	12 (3,8)	**22 (4,2)**
d630	**Preparing meals**[1]	10 (4,8)	12 (3,8)	**22 (4,2)**
d640	**Doing housework**[1,χ]	5 (2,4)	**24 (7,5)**	**29 (5,5)**
d650	**Caring for household objects**[1]	11 (5,3)	13 (4,1)	**24 (4,6)**
d660	Assisting others[1]	1 (0,5)	0 (0)	1 (0,2)
Domain 7: Interpersonal interactions and relationships		3 (1,4)	9 (2,8)	12 (2,3)
d710	Basic interpersonal interactions[1]	0 (0)	1 (0,3)	1 (0,2)
d720	Complex interpersonal interactions[1]	0 (0)	1 (0,3)	1 (0,2)
d750	Informal social relationships[1]	3 (1,4)	1 (0,3)	4 (0,8)
d760	Family relationship[1,2]	0 (0)	3 (0,9)	3 (0,6)
d770	Intimate relationship[1]	0 (0)	3 (0,9)	3 (0,6)
Domain 8: Major life areas		5 (2,4)	15 (4,7)	20 (3,8)
d825	Vocational training[1]	0 (0)	1 (0,3)	1 (0,2)
d839	Education, other specified and unspecified	0 (0)	3 (0,9)	3 (0,6)
d845	Acquiring, keeping and terminating a job[1]	0 (0)	1 (0,3)	1 (0,2)
d850	Remunerative employment[1,2]	4 (1,9)	5 (1,6)	9 (1,7)
d855	Non-remunerative employment	1 (0,5)	1 (0,3)	2 (0,4)
d860	Basic economic self-sufficiency[1]	0 (0)	4 (1,3)	4 (0,8)
Domain 9: Community, social and civic life		53 (25,5)	93 (29,2)	146 (27,7)
d910	Community Life[1]	0 (0)	1 (0,3)	1 (0,2)
d920	**Recreation and leisure**[1]	**53 (25,5)**	**92 (28,8)**	**145 (27,5)**
Total	**Most important problems**	**208 (100)**	**319 (100)**	**527 (100)**

[1]Included in the comprehensive ICF core Set, [2]Included in the brief ICF core Set, n ≥ 20 as bold, [χ] Chi-squared moderate vs severe p<0,05

5.3.2 Perceived participation and autonomy measured with IPA

In the IPA questionnaire, most participants reported that their autonomy indoors, measured by several items related to self-care and mobility, was very good or good (Table 9). Most of the social relations items were also reported as very good or good by over 70% of participants. Exceptions were the items intimate relationship, which 49% reported as fair, poor or very poor, and helping and supporting people, which 57% reported as fair, poor or very poor. Reports of fair, poor or very poor participation were mostly reported for items in the domains of family role and autonomy outdoors. In the domain of work and education, more than half of the participants reported the item getting or keeping a wanted job as fair, poor or very poor (74% of participants) and 49% of those in work (n=72) reported their prospects of getting a different job as fair, poor or very poor.

People with severe disability gave statistically significantly lower evaluations of their participation than people with moderate disability, in the following six IPA items: 1) washing, dressing, grooming oneself in the way one wants and 2) when one wants, 3) going to the toilet when one needs to, 4) doing home repairs and maintenance, 5) intimate relationship and 6) getting or keeping a wanted job. In contrast, people with moderate disability gave statistically significantly lower evaluations of receiving respect from acquaintances than people with severe disability.

TABLE 9 IPA-measured participation levels, reported by people with mild (n=8), moderate (n=62) and severe disability (n=124)

ICF code	**Category title**	**IPA items per participation domain**	**Very good or good n (%)**				**Fair, poor or very poor n (%)**			
			Mild disability, n=8 (%)	Moderate disability, n=62 (%)	Severe disability, n=124 (%)	Total, n=194 (%)	Mild disability, n=8 (%)	Moderate disability, n=62 (%)	Severe disability, n=124 (%)	Total, n=194 (%)
		Autonomy indoors*								
d460	Moving around in different locations[1]	Getting around indoors where one wants	8 (100)	44 (71)	75 (61)	127 (66)	0 (0)	18 (29)	49 (40)	67 (35)
d460	Moving around in different locations[1]	Getting around indoors when one wants	7 (88)	47 (76)	84 (68)	138 (71)	1 (12)	15 (24)	40 (32)	56 (29)
d510, d520, d540	Washing oneself[1], Caring for body parts[1], Dressing[1]	Washing, dressing, grooming oneself the way one wants [x]	8 (100)	51 (82)	83 (67)	142 (73)	0 (0)	11 (18)	41 (33)	52 (27)
d510, d520, d540	Washing oneself[1], Caring for body parts[1], Dressing[1]	Washing, dressing, grooming when one wants [x]	7 (88)	51 (82)	82 (66)	140 (72)	1 (12)	11 (18)	42 (34)	54 (28)
d410	Changing basic body position[1]	Going to bed when one wants	7 (88)	53 (86)	98 (79)	158 (81)	1 (12)	9 (14)	26 (21)	36 (19)
d530	Toileting[1]	Going to toilet when one needs to [x]	7 (88)	58 (94)	94 (76)	159 (82)	1 (12)	4 (6)	30 (24)	35 (18)
d550, d560	Eating[1], Drinking[1]	Eating and drinking when one wants to	6 (75)	55 (89)	99 (80)	160 (83)	2 (25)	7 (11)	25 (20)	34 (17)
		Family role*								
d620, 630, d640, d650	Acquisition of goods and services[1], Preparing meals[1], Doing housework[1], Caring for household objects[1]	**Contributing to looking after the home**	5 (63)	24 (39)	37 (30)	66 (34)	3 (37)	**38 (61)**	**87 (70)**	**128 (66)**

continues

TABLE 9 continues

ICF code	**Category title**	**IPA items per participation domain**	**Very good or good n (%)**				**Fair, poor or very poor n (%)**			
			Mild disability, n=8 (%)	Moderate disability, n=62 (%)	Severe disability, n=124 (%)	Total, n=194 (%)	Mild disability, n=8 (%)	Moderate disability, n=62 (%)	Severe disability, n=124 (%)	Total, n=194 (%)
d630,	Preparing meals[1]	Doing minor household jobs in the way one wants	6 (75)	54 (87)	98 (79)	158 (81)	2 (25)	8 (13)	26 (21)	36 (19)
d620, 630, d640, d650	Acquisition of goods and services[1], Preparing meals[1], Doing housework[1], Caring for household objects[1]	Doing heavy housework jobs in the way one wants	6 (75)	29 (47)	68 (55)	103 (53)	2 (25)	**33 (53)**	56 (45)	91 (47)
d620, 630, d640, d650	Acquisition of goods and services[1], Preparing meals[1], Doing housework[1], Caring for household objects[1]	**Getting housework done when one wants to**	6 (75)	28 (45)	60 (48)	94 (49)	2 (25)	**34 (55)**	**64 (52)**	**100 (51)**
d650	Caring for household objects[1]	**Home repairs and maintenance** *x*	6 (75)	32 (52)	41 (33)	79 (41)	2 (25)	30 (48)	**83 (67)**	**115 (59)**
d6	Domestic life	**Fulfilling one's role at home**	5 (63)	29 (47)	55 (44)	89 (46)	3 (37)	**33 (53)**	**69 (56)**	**105 (54)**
d870	Economic self-sufficiency[1]	Spending one's income as one wishes	7 (88)	54 (87)	113 (91)	174 (90)	1 (12)	8 (13)	11 (9)	20 (10)
		Autonomy outdoors*								
d920	Recreation and leisure[1]	**Visiting friends when one wants to**	5 (63)	30 (48)	50 (40)	85 (44)	3 (37)	**32 (52)**	**74 (60)**	**109 (56)**
d920	Recreation and leisure[1]	**Going on trips and holidays one wants**	4 (50)	18 (29)	37 (30)	59 (30)	**4 (50)**	**44 (71)**	**87 (70)**	**135 (70)**
d920	Recreation and leisure[1]	**Spending leisure time in the way one wants**	6 (75)	34 (55)	62 (50)	102 (53)	25 (2)	28 (45)	**62 (50)**	92 (47)

continues

TABLE 9 continues

ICF code	**Category title**	**IPA items per participation domain**	**Very good or good n (%)**				**Fair, poor or very poor n (%)**			
			Mild disability, n=8 (%)	Moderate disability, n=62 (%)	Severe disability, n=124 (%)	Total, n=194 (%)	Mild disability, n=8 (%)	Moderate disability, n=62 (%)	Severe disability, n=124 (%)	Total, n=194 (%)
d750	Informal social relationships[1]	**Frequency of social contacts**	5 (63)	34 (55)	60 (49)	99 (51)	3 (37)	28 (45)	**63 (51)**	94 (49)
not classified		**Living life in the way one wants**	5 (63)	29 (48)	64 (52)	98 (51)	3 (37)	**32 (52)**	60 (48)	95 (49)
		Social relations*								
d750, d760	Informal social relationships[1], Family relationship[1,2]	Communication on equal terms with close people	7 (88)	45 (73)	96 (78)	148 (77)	1 (12)	17 (27)	27 (22)	45 (23)
d750, d760	Informal social relationships[1], Family relationship[1,2]	Relationship with close people	7 (88)	53 (86)	106 (86)	166 (86)	1 (12)	9 (14)	18 (14)	28 (14)
d710	Basic interpersonal interactions[1]	Respect from close people	7 (88)	42 (68)	100 (81)	149 (77)	1 (12)	20 (32)	24 (19)	45 (23)
d740	Formal relationships	Relationship with acquaintances	7 (88)	49 (79)	101 (82)	157 (81)	1 (12)	13 (21)	23 (18)	37 (19)
d710	Basic interpersonal interactions[1]	Respect from acquaintances χ	6 (75)	36 (58)	90 (73)	132 (68)	2 (25)	26 (42)	34 (27)	62 (32)
d770	Intimate relationship[1]	**Intimate relationship** χ	6 (75)	40 (65)	54 (44)	100 (52)	2 (25)	22 (35)	**70 (56)**	94 (49)
d660	Assisting others[1]	**Helping and supporting people**	6 (75)	25 (40)	52 (42)	83 (43)	2 (25)	**37 (60)**	**71 (58)**	**110 (57)**
		Work and education*								
d845	Acquiring, keeping and terminating a job[1]	**Getting or keeping wanted job** (n=191) χ	5 (63)	21 (34)	24 (20)	50 (26)	3 (37)	**40 (66)**	**98 (80)**	**141 (74)**

continues

TABLE 9 continues

ICF code	**Category title**	**IPA items per participation domain**	**Very good or good n (%)**				**Fair, poor or very poor n (%)**			
			Mild disability, n=8 (%)	Moderate disability, n=62 (%)	Severe disability, n=124 (%)	Total, n=194 (%)	Mild disability, n=8 (%)	Moderate disability, n=62 (%)	Severe disability, n=124 (%)	Total, n=194 (%)
d850, d855	Remunerative employment[1,2], Non-remunerative employment	**Doing work the way one wants**** (n=72)	4 (57)	15 (65)	21 (50)	40 (56)	3 (43)	8 (35)	**21 (50)**	32 (44)
d740	Formal relationships	Contacts with colleagues**(n=72)	6 (86)	18 (78)	37 (88)	61 (85)	1 (14)	5 (22)	5 (12)	11 (15)
d845	Acquiring, keeping and terminating a job[1]	Achieving or maintaining a position one wants** (n=72)	4 (57)	17 (74)	26 (62)	47 (65)	3 (43)	6 (26)	16 (38)	25 (35)
d845	Acquiring, keeping and terminating a job[1]	**Getting a different job****(n=72)	2 (29)	10 (44)	11 (26)	23 (32)	**5 (71)**	**13 (57)**	**31 (74)**	**49 (68)**
d825, d830, d840	Vocational training[1], Higher education[1], Apprenticeship (work preparation)	**Getting training or education one wants***** (n=96)	3 (50)	11 (34)	23 (40)	37 (39)	**3 (50)**	**21 (66)**	**35 (60)**	**59 (61)**

*IPA Participation Domain; **Respondents were instructed not to answer these items if they did not have paid or voluntary work; ***98 persons reported that this item was not relevant to them; [1]Included in the comprehensive ICF core set.; [2]Included in the brief ICF core set.; items ≥ 50 % of people assessed as fair, poor or very poor are bolded.; χ Chi-squared moderate vs severe p<0,05

5.3.3 Confirmation of the comprehensive and brief ICF core set for MS: activities and participation

Forty-one of the 43 second-level categories of activities and participation identified by the COPM as a problem in daily living are included in the comprehensive ICF core set (Table 10). In comparison, the 23 IPA second-level categories activities and participation reported by over 50 percent of the participants as fair, poor or very poor, are included in the comprehensive ICF core set (Table 10).

TABLE 10 Activities and participation categories from the ICF comprehensive and brief core sets included in the COPM and IPA data

ICF code	Category title	Included in COPM data	Included in IPA data
Comprehensive core set			
d110	Watching		
d155	Acquiring skills	x	
d160	Focusing attention		
d163	Thinking		
d166	Reading	x	
d170	Writing	x	
d175	Solving problems		
d177	Making decisions		
d210	Undertaking a single task	x	
d220	Undertaking multiple tasks		
d230	Carrying out daily routine	x	
d240	Handling stress and other psychological demands	x	
d330	Speaking		
d350	Conversation	x	
d360	Using communication devices and techniques		
d410	Changing basic body position	x	x
d415	Maintaining a body position	x	
d420	Transferring oneself	x	
d430	Lifting and carrying objects	x	
d440	Fine hand use	x	
d445	Hand and arm use	x	
d450	Walking	x*	
d455	Moving around	x	
d460	Moving around in different locations	x	x
d465	Moving around using equipment	x	
d470	Using transportation	x	
d475	Driving	x	
d510	Washing oneself	x	x*
d520	Caring for body parts	x	x*
d530	Toileting	x	x*

continues

TABLE 10 continues

ICF code	Category title	Included in COPM data	Included in IPA data
d540	Dressing	x	x*
d550	Eating	x	x
d560	Drinking		x
d570	Looking after one's health	x	
d620	**Acquisition of goods and services**	**x**	**x**
d630	**Preparing meals**	**x**	**x**
d640	**Doing housework**	**x***	**x**
d650	**Caring for household objects**	**x**	**x***
d660	**Assisting others**	**x**	**x**
d710	Basic interpersonal interactions	x	x*
d720	Complex interpersonal interactions	x	
d750	Informal social relationships	x	x
d760	Family relationships	x	x
d770	**Intimate relationships**	**x**	**x***
d825	**Vocational training**	**x**	**x**
d830	Higher education		x
d845	**Acquiring, keeping and terminating a job**	**x**	**x***
d850	**Remunerative employment**	**x**	**x**
d860	Basic economic transactions	x	
d870	Economic self-sufficiency		x
d910	Community life	x	
d920	**Recreation and leisure**	**x**	**x**
d930	Religion and spirituality		
	Total number of categories	42	23
Brief core set			
d175	Solving problems		
d230	Carrying out daily routine	x	
d450	Walking	x*	
d760	Family relationships	x	x
d850	**Remunerative employment**	**x**	**x**
	Total number of categories	4	2

IPA items assessed as fair, poor or very poor by ≥ 50 % of people with moderate and/or severe disability in also included in the COPM data are bolded
* Difference between people with moderate and severe disability was found

The categories d839 education, and d855 non-remunerative employment identified by the COPM are not included in the comprehensive ICF core set. The IPA items coded as d740 formal relationships, d840 apprenticeship (work preparation) and d855 non-remunerative employment are also not included in the comprehensive ICF core set. In turn, the comprehensive ICF core set includes nine second-level categories that did not appear in the COPM sample or among the IPA items: d110 watching, d160 focusing attention, d163 thinking, d175 solving problems, d177 making decisions, d220 undertaking multiple tasks, d330 speaking, d360 using communication devices and techniques and d930 religion and spirituality.

Four of the five second-level categories of the brief ICF core set appeared in the COPM sample: d230 carrying out daily routines, d450 walking, d760 family relationship and d850 remunerative employment. Similarly, the IPA items contained two of the five second-level categories of the brief ICF core set: d760 family relationship and d850 remunerative employment. The category d175 solving problems, also included in the brief ICF core set, was not in either the COPM or IPA.

5.4 Predictors of participation and autonomy (III)

The correlation analysis revealed statistically significant associations between the IPA domains (dependent variables), ranging from 0.46 to 0.73 ($p<0.01$). In addition, the WHOQOL-BREF physical, psychological, social and environment and the MSIS-29 physical and psychological predictor variables were significantly associated with each other, with correlations ranging from 0.21 to 0.59 ($p<0.01$).

Consequently, a structural equation model (model 1) based on two latent factors was constructed. The reliability of the IPA domains and MSIS-29 was high (range from 0.85 to 0.93) in this sample, enabling the creation of latent factors. The WHOQOL-BREF data contained only the domain scores. The IPA domains yielded one latent factor, which was labelled "participation and autonomy", while the domains of the WHOQOL-BREF and the MSIS-29 formed a single shared latent factor. Although the EDSS significantly correlated only with the IPA domain autonomy indoors, the WHOQOL-BREF physical domain and physical impact in the MSIS-29, the EDSS was added to the model as an independent variable.

The constructed model (model 1) did not fit to the data (Table 11) and was therefore modified. According to the standardized residuals, four specific factors (S1, S2, S3 and S4) were added to the model. Moreover, in model 1, the EDSS did not significantly predict the latent factor "participation and autonomy". However, the MPlus modification indices indicated that the EDSS predicted the IPA domain autonomy indoors.

TABLE 11 Statistics for a structural equation model based on two latent factors (M1) and the modified model (M2)

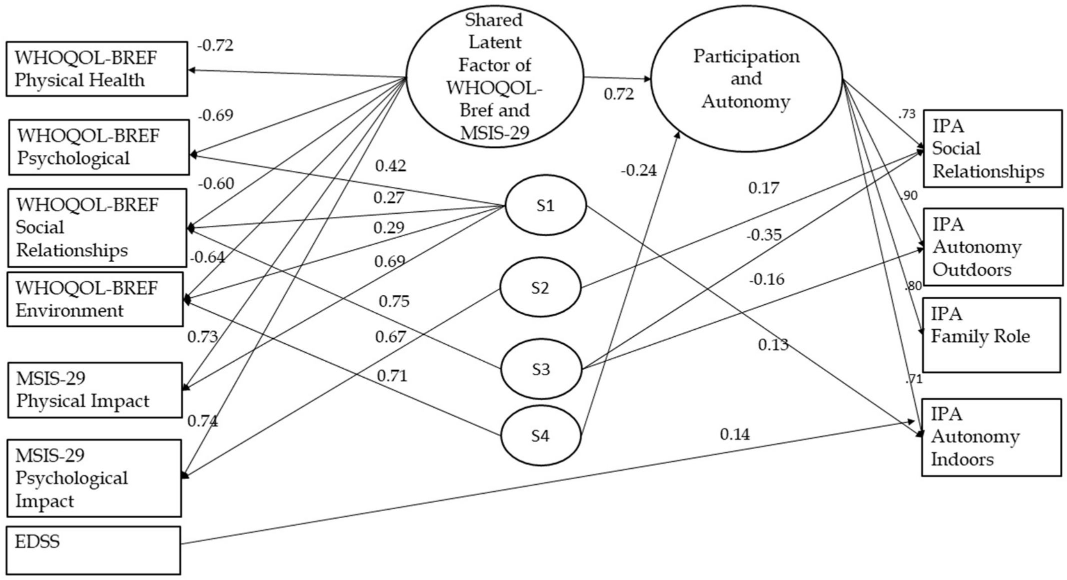
Model	χ^2	df	$\chi2/df$	p-value	CFI	TLI	RMSEA	SRMR
M1	234,77	43	5.45	< 0.001	0.80	0.75	0.15	0.10
M2	46.729	30	1.56	< .026	0.98	0.97	0.05	0.04

M1 = A structural equation model based on two latent factors

M2 = A structural equation model based on two latent factors with modifications (for modifications, see Figure 6)

$\chi2$ = Chi-squared statistic, df = Degrees of freedom, CFI = Comparative fit index, TLI = Tucker-Lewis index, RMSEA = Root mean square error of approximation, SRMR = Standardized root mean square residual

The final structural equation model (model 2) showed good fit to the data (Figure 6). All the goodness-of-fit indices except the chi-square value supported the model (Table 11). The normalized residuals were distributed as expected, which also supported the model.



EDSS=Expanded Disability Status Scale, IPA=Impact on Participation and Autonomy, WHOQOL-BREF =WHO Quality of Life BREF, MSIS-29=Multiple Sclerosis Impact Scale 29

FIGURE 6 The results of modified structural equation model for the prediction of participation and autonomy for the shared factor of the WHOQOL-BREF and MSIS-29 domains and the EDSS.

Collectively, the WHOQOL-BREF domains and the MSIS-29 domains predicted participation and autonomy as measured with the IPA. The whole model accounted for 57.2 % of the variance in the latent factor “participation and autonomy”. The shared latent factor of the WHOQOL-BREF and MSIS-29 predicted the latent factor “participation and autonomy” (explanation rate 51.7 %). Moreover, the WHOQOL-BREF domain environmental factors (specific factor 4), predicted “participation and autonomy” (explanation rate 5.5 %). In addition, three specific factors predicted different domains of the IPA. The EDSS predicted only the IPA domain autonomy indoors.

5.5 Changes in everyday activities of daily life (IV) during the two-year multidisciplinary rehabilitation

No significant group-by-time interaction was found in the assessments of COPM performance, (p=0.91) or COPM satisfaction (p=0.92) (Figures 7 and 8).

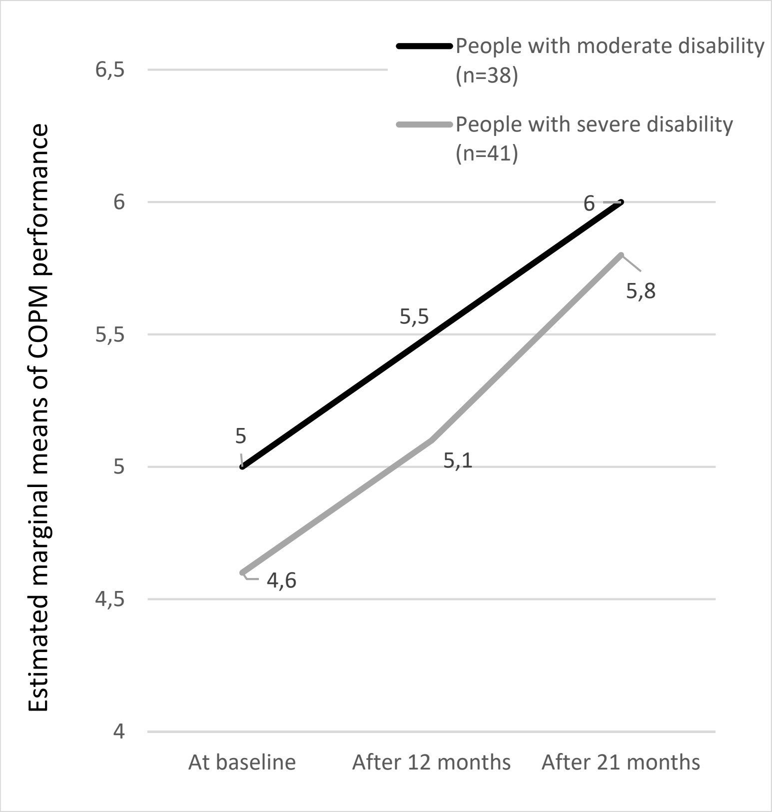


FIGURE 7 Comparisons of COPM performance between the MS groups of moderate (n=38) and severe (n=41) disability during the 21-month rehabilitation period.

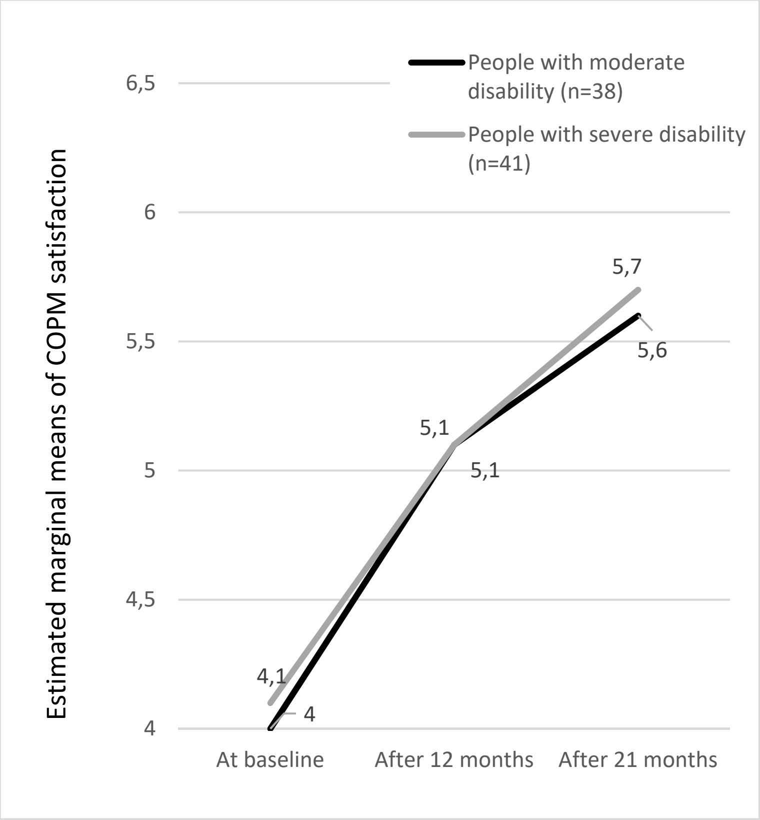


FIGURE 8 Comparisons of COPM satisfaction between the MS groups of moderate (n=38) and severe (n=41) disability during the 21-month rehabilitation period.

The main effect of time in the COPM performance and satisfaction scores was statistically significant (both p<0.001). There was not a statistically significant difference in COPM performance between groups (p=0.26) or in COPM satisfaction between groups (p=0.80).

Post-hoc analysis with Bonferroni adjustment revealed statistically significantly improved COPM performance of the moderately disabled MS participants at 21 months from baseline (1.0 (95% CI, 0.2 to 1.8), p= 0.006). COPM performance in the participants with severe disability had improved at 21 months from baseline by 1.2 ((0.4 to 1.9), p=.001) and from 12 months to 21 months by 0.7 ((0.1 to 1.3), p=.016). COPM satisfaction of moderately disabled people had improved at 21 months from baseline (1.5 (0.6 to 2.5), p<.001), with statistically significant improvement at 12 months from baseline (1.1 (0.3 to 2.0), p=.004). In the severely disabled group the respective improvements in satisfaction were 1.6 ((0.7 to 2.6), p<.001), and 1.0 ((0.2 to 1.8), p=.007).

No statistically significant differences were observed in the numbers of people with clinically relevant changes in the moderately and severely disabled groups. A clinically relevant change (over the threshold of 1.4 points) in their COPM performance scores was achieved by 35 (44 %) participants. A total of 31 (39 %) participants' COPM satisfaction scores reached the threshold value for clinically relevant change, i.e. 1.9 (Eyssen et al. 2011a).

5.6 Reasons for changes in everyday activities (IV) during the two-year multidisciplinary rehabilitation

Participants reported a total of 351 reasons for change in everyday activities. The reasons linked to ICF components and domains are shown in Table 12. The reasons given by participants for improving or maintaining stable performance were most often linked to the ICF components environmental and personal factors. Reasons for declining performance were most commonly linked to the ICF component personal factors.

Environmental factors reported as improving performance were commonly linked to ICF domain e1 products and technology (e.g. acquiring new devices or environmental modification) and e3 support and relationships (e.g. getting appropriate personal assistance). Reasons for improved performance commonly linked to personal factors were doing daily tasks in a new way, and dealing with situation in a new way. In addition, general state of health was reported to affect both improvement and decline in the performance of activities. Reasons linked to ICF body functions concerned mental functions such as energy, drive, and pain. Only 5% of reasons were linked to the ICF domain activity and participation, and the most common of these reasons concerned self-care via maintaining physical fitness and work-life.

TABLE 12 The ICF components and domains linked to perceived reasons for changes in performance of daily activities

ICF component and domain	Improving n (%)		Stable n (%)		Declining n (%)	
	Moderate disability (n=38)	Severe disability (n=41)	Moderate disability (n=38)	Severe disability (n=41)	Moderate disability (n=38)	Severe disability (n=41)
b Body functions	8 (9)	11 (14)	4 (9)	4 (7)	3 (7)	3 (10)
b1 Mental functions	7 (7)	11 (14)	3 (7)	3 (5)	3 (7)	3 (10)
b2 Sensory functions and pain	1 (1)	0 (0)	1 (2)	1 (2)	0 (0)	0 (0)
d Activities and participation	7 (7)	2 (3)	7 (15)	2 (4)	0 (0)	2 (6)
d1 Learning and applying knowledge	1 (1)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
d4 Mobility	0 (0)	0 (0)	1 (2)	1 (2)	0 (0)	1 (3)
d5 Self-care	6 (6)	0 (0)	3 (7)	0 (0)	0 (0)	0 (0)
d7 Interpersonal interactions and relationships	0 (0)	1 (1)	1 (2)	0 (0)	0 (0)	0 (0)
d8 Major life areas	0 (0)	1 (1)	2 (4)	1 (2)		1 (3)
e Environmental factors	42 (44)	39 (51)	10 (21)	15 (27)	6 (13)	1 (3)
e1 Products and technology	25 (26)	12 (16)	9 (19)	14 (25)	3 (7)	1 (3)
e2 Natural environment and human-made changes to environment	2 (2)	2 (3)	0 (0)	0 (0)	0 (0)	0 (0)
e3 Support and relationships	10 (11)	19 (25)	1 (2)	1 (2)	3 (6)	0(0)
e5 Services, systems and policies	5 (5)	6 (8)	0 (0)	0 (0)	0 (0)	0 (0)
p Personal factors	38 (40)	24 (32)	26 (55)	35 (62)	37 (80)	25 (81)
Total number of reasons	95 (100)	76 (100)	47 (100)	56 (100)	46 (100)	31(100)

6 DISCUSSION

The main purpose of this dissertation was twofold: first, to explore the participation and perceived functioning of moderately and severely disabled people with MS in everyday life, and second, to investigate the effect of a two-year multidisciplinary rehabilitation on everyday activities.

According to the results of this study, the Impact on Participation and Autonomy, IPA questionnaire showed good construct validity as a measure of MS individuals' perceived participation and autonomy. In addition, the IPA showed acceptable reliability. The data collected via two self-assessment measures – the IPA and the Canadian Occupational Performance Measure, COPM – demonstrate the diversity of challenges in activities and participation in everyday life experienced by people with MS. The components of the ICF categories of Activities and Participation included in the comprehensive and brief core set for MS were validated by the empirical data collected with the COPM. Furthermore, perceived quality of life, measured with the WHOQOL-BREF, and the physical and psychological impact of multiple sclerosis, measured with the Multiple Sclerosis Impact Scale (MSIS-29), predicted perceived participation and autonomy. Interestingly, disease severity, measured with the EDSS, only predicted participation and autonomy in indoor activities. Moreover, gender did not predict participation and autonomy.

The results of the prospective follow-up study indicated improved performance and satisfaction with everyday activities of the MS participants during two-year multidisciplinary rehabilitation. The improvement reported by the two groups of moderately and severely disabled people with MS did not differ from each other. The self-reported reasons for changes in everyday activities were diverse across the study population.

6.1 Self-perceived participation in everyday life of people with MS assessed with valid measures

Two different kinds of self-assessment measures of participation were chosen: the COPM, which is based on a semi-structured interview and the IPA questionnaire. Different definitions and conceptualizations of participation produce different results (Stallinga et al. 2014), and therefore two measures which capture different aspects of participation were selected for use in this study. Thus, it was assumed that a deeper understanding of the participation of people with MS would be gained by comparing the results of two different measures.

The COPM has been used in numerous studies and has been shown to have acceptable validity and reliability (Carswell et al. 2004). Furthermore, the COPM has been found to enhance occupation-focused and client-centered clinical practice (Colquhoun et al. 2012, Enemark Larsen et al. 2018). The IPA, in turn, was translated into Finnish for the purposes of the multidisciplinary group rehabilitation described in this study. Therefore, the study included tests of the psychometric properties of the IPA. The main concern was to verify the construct validity and the reliability of the Finnish version of the IPA. A four-factor model, comprising the IPA domains autonomy indoors, family role, autonomy outdoors, and social life and relationships was tested. The work and education opportunities domain was excluded from the analysis as the questions were answered by only a minority of the participants. All the fit indices (Standardized Root Mean Square Residual, Comparative Fit Index, Tucker-Lewis Index, Root Mean Square Error of Approximation) with the exception of the $\chi 2$-value showed acceptable model fit. However, $\chi 2$ and degrees of freedom ratio values lower than two are considered to represent minimal model fit (Byrne 1991). The fit of the model was also supported by the lower number of normalized residuals with an absolute value over two than had been expected and by the normal distribution of residuals. This finding is in line with the outcome of a previous study (Cardol et al. 2001) which included the same domains as in this study and with a study which also included the work and education opportunities domain (Sibley et al. 2006b).

The CFA results supported the notion that participation is a complex phenomenon. In addition to the original main factor, three of the IPA items also loaded on another theoretically relevant factor in the modified model. First, the loading of the item chances to visit relatives and friends when one wants was clearly stronger on the original main factor, the autonomy outdoors domain (0.55), than on the other factor, the autonomy indoors domain (0.25).

Second, the original main factor of the item spending one's income as one wishes is in the family role domain. However, the item loaded more strongly on the autonomy outdoor domain (0.59) than on the family role domain (-0.01). A logical explanation for this result can be offered. It can be hypothesized that because most of the participants were on a disability pension, a low income is fact of life for them. In addition, the items of the autonomy outdoors domain chances to visit relatives and friends, use of leisure time in the way on wants and chances to see other people as often as one wants all depend on the financial resources available to them.

Third, the item minor housework loaded less on the original main factor, i.e. the family role domain (0.25) than on the autonomy indoors domain (0.57). The demands of minor housework, operationalized as light tasks around the house, e.g. making tea or coffee, are closer to the activities of the autonomy indoors domain, such as getting up and going to bed or eating and drinking, than to the demands of activities in the family role domain, such as contributing to looking after the home.

The same two IPA items of spending one’s income as one wishes and minor housework, have also been considered in previous studies. In a study of people with multiple sclerosis, rheumatoid arthritis, spinal cord injury, and general practice attendees, these two items loaded weakly on the family role domain. However, the items showed no cross loadings on any factor other than the main factor (Sibley et al. 2006). A few reasons for the weak loading of the item spending one’s income as wished have been given. One is that the item spending income as one wishes may have been variously interpreted. Some may have thought about their physical capacity to carry out transactions, while others may have focused on the ability to make decisions about how to spend one’s income (Sibley et al. 2006). Moreover, it has been observed that respondents have experienced talking about financial issues as uncomfortable, and that this may have contributed to unpredictability in the factor loading (Fallahpour et al. 2011). It is noteworthy that in two studies conducted using Rasch analysis, the item spending one’s income as one wishes did not meet the goodness-of-fit criterion (Lund et al. 2007, Fallahpour et al. 2011).

Therefore, in such cases, where there may be multiple reasons why an item does not load on the main factor, larger samples with different clinical groups are needed. However, according to the findings of this and previous studies (Sibley et al. 2006, Lund et al. 2007, Fallahpour et al. 2011), in clinical practice, if individuals with MS reports challenges in items of the IPA autonomy outdoors domain, their financial situation merits discussion. Correspondingly, if restrictions are perceived in the autonomy indoors domain, they may also be perceived in the item minor housework.

All the substantial correlations (over 0.40) between the residuals of the IPA items were found for items which loaded on the same factor. For example, in the social relations domain, the correlation was high between the residuals of the items relations with close people and respect from close people, and between the residuals of the items relations with acquaintances and respect from acquaintances. If a client perceives participation restriction in a certain domain, it is recommended that the answers given to single items are considered.

6.2 Challenges in self-perceived participation in everyday life

The results of the two different self-report measures of participation used in this study support those of recent studies: people with MS face many challenges in everyday life and these challenges vary greatly between individuals (Lexell et al. 2014, Dehghan et al. 2019). It can be argued that both the COPM and the IPA are relevant measures for assessing the participation of people with MS because they underline the diversity of activities and areas of participation that are individually experienced as important.

In both the moderate and severe disability groups, the most frequently reported restrictions on participation were in the IPA family role domain, in other words household tasks, and the IPA autonomy outdoors domain, such as visiting friends, going on holidays or spending leisure time. Moreover, individuals in both groups reported restrictions in intimate relationships, supporting other people and working life. Similarly, the most frequently reported problems in daily life measured with COPM concerned household activities and leisure activities, and also mobility. These findings on restrictions in social participation are in line with those of previous studies (Holper et al. 2010, Cattaneo et al. 2017). In a study of 205 participants with MS, the most frequently reported participation restrictions were in the areas of recreation and leisure, community life, remunerative employment, and intimate relationships (Holper et al. 2010). Likewise, a study of 98 participants with MS showed that, when measured with Community Integration Scale, social participation was perceived as more restricted than home integration (Cattaneo et al. 2017).

Earlier studies have yielded diverse knowledge on the connections between participation and disease severity. While, severity of symptoms was not found to be associated with the importance attributed to activities (Yorkston et al. 2008), participation restrictions have been found to increase along with disease severity (Cattaneo et al. 2017). In the present sample, the COPM and IPA showed only few differences between people with moderate and severe disability in perceived problems in participation in daily life. Moreover, perceived participation of people with the three different forms of MS – relapsing-remitting multiple sclerosis (RRMS), primary-progressive multiple sclerosis (PPMS) and secondary progressive multiple sclerosis (SPMS) – also showed few differences (Holper et al. 2010). As in the present sample, a previous study showed that disease severity measured with the EDSS differs across different MS forms. Specifically, disease severity is lower in people with RRMS and higher in people with SPMS (Holper et al. 2010). Disease severity may therefore have some impact on the areas of restricted participation. However, there were no differences between people with moderate and severe disability in most of the problems reported. It should be kept in mind that individual differences in perceived restrictions on participation seem to be more prominent than those associated with disease severity.

The comprehensive and brief ICF core sets for MS were developed to help professionals target evaluations and interventions to issues of the greatest importance for people with MS (Kesselring et al. 2008, Coenen et al. 2011). The present results demonstrate the relevance for MS of both the current ICF lists of activities and the comprehensive and brief ICF core set participation categories. The data gathered using the IPA and COPM captured 44 of the 53 categories of the comprehensive ICF core set for MS and four of the five categories of the brief ICF core set for MS.

Nine of the comprehensive ICF core set categories were not present in the perspectives of the present participants, as the most important activity limitations and participation restrictions in the COPM data or were not included in the IPA items. The ICF defines participation as involvement in a life situation, and activity as the execution of a task or an action by an individual. Most of these categories are more related to such ICF activities as d110 watching, d160 focusing attention, d163 thinking, d175 solving problems, d177 making decisions and d220 undertaking multiple tasks than to participation. The COPM emphasizes daily activities that the client needs, wants or is expected to do yet is unable to accomplish satisfactorily. These activities are usually related to contextual factors and therefore to participation. In the COPM assessment, the person is encouraged to contextualize the problem. For example, if a person reports having difficulties in focusing their attention, the evaluator will ask the person to talk about a particular activity and/or situation affected by the difficulty. The person might then describe life situations such as conversing with friends or reading a fairy tale to children.

The participants in this study did not have major problems in communication, which may explain why they did not report ICF activities d330 speaking or d360 using communication devices and techniques as among the most important problems in the COPM assessment. In this sample, d930 religion and spirituality, which is not included in the IPA, did not emerge as a problem in the COPM assessment. However, the inclusion of d930 religion and spirituality in the comprehensive ICF core set for MS is relevant as it has been found that religion and spirituality have both positive and negative associations with disability (Chen et al. 2011, Büssing et al. 2013).

The brief ICF core set for MS includes five categories of the activities and participation component (d175 solving problems, d230 carrying out daily routines, d450 walking, d760 family relationship and d850 remunerative employment). In the COPM data four of the five categories were present in the sample; category d175 solving problems did not appear. The IPA contains only the categories d760 family relationship and d850 remunerative employment.

The commonest category reported in the COPM data, d920 recreation and leisure, is not included in the brief ICF core set. In the IPA data, the items visiting friends when one wants and going on trips and holidays one wants, which are linked to category d920 recreation and leisure, were reported as difficult. Previous research has also shown that activities linked to category d920 recreation and leisure are highly relevant to people with MS (Khan & Pallant 2007, Holper et al. 2010, Coenen et al. 2011). Therefore, the idea of adding this category to the brief ICF core set for MS merits consideration.

The present findings support the application of the ICF core sets for MS in clinical practice. However, the results of this and a previous study (Lexell et al. 2009) on personal variation in the content of perceived problems should be taken into account when using the ICF core sets. Moreover, the complex and dynamic nature of daily activities and participation (Hammel et al. 2008) should be considered in clinical practice and not routinely applied to the ICF core sets. The ICF was not developed as a tool for assessment (Grill & Stucki 2011) and the ICF categories are not meant to be directly applied in practice. However, using ICF as a frame of reference for assessment can be recommended as it offers a comprehensive and holistic view of functioning and thus a tool for identifying possible factors facilitating or hindering participation (Svestkova et al. 2010).

In summary, the findings of this study show that these two self-assessment measures, the COPM and the IPA, which focus on different aspects of activity and participation support the implementation of client-centered and person-centered clinical practice in the case of people with MS. Both the IPA and COPM are in line with the ICF core sets. They draw attention to the areas included in the ICF core sets for MS. In addition, these measures highlight the similarities and differences in problems experienced by people differing in disability status.

6.3 Predictors of participation and autonomy

According to the results of this study, quality of life measured with the WHOQOL-BREF and the impact of disease measured with MSIS-29 predict participation and autonomy. All three measures (IPA, WHOQOL-BREF and MSIS-29) applied in this study are patient-reported, subjective measures, which may partially explain the strong associations. This study shows that environmental factors measured with WHOQOL-BREF are associated with participation and autonomy. This finding is consistent with previous studies that have identified associations between environmental barriers and perceived participation of people with a chronic condition (Larsson Lund & Lexell 2009, Hollingsworth & Gray 2010, Hammel et al. 2015). Moreover, both physical and social environmental factors have been found to play an important role for people with MS (Plow et al. 2015) as well as for stroke survivors (Jellema et al. 2016) in engaging in meaningful and valued activities. In addition, the importance of engaging in social activities was highlighted in the reviewed study that identified an association between social participation and the physical component of health-related quality of life (measured with the 36-item Short-Form (SF-36) health survey) (Mikula et al. 2015).

For the reasons given above, there is a clear need to use measures that capture the relationships between environmental factors and participation. However, it has been claimed that the existing measures do not take the dynamic and complex nature of this relationship into account and thus there is a need to develop measures informed by ecological, life span, and life course models (Magasi et al. 2015). Instead of developing new measures it is worth considering using existing holistic, practical models to guide assessment and intervention practice beside the ICF classification. Relevant holistic models, such as the Person-Environment-Occupation Model (Law et al. 1996) or the Occupational Therapy Intervention Process Model (Fisher & Marterella 2019), emphasize the role of the environment. It would be good practice to evaluate the relevant environmental factors if a person with MS reports problems with participation and autonomy in everyday life. Thus, actions to lessen environmental barriers could be applied, for example, in modifying the environment or educating family members and other close persons.

An interesting finding was that disease severity is not the most important factor predicting participation and autonomy. Associations were found only between the IPA autonomy indoors domain and disease severity measured with the EDSS. The items that comprise the autonomy indoors domain, such as washing and dressing or toileting, are more dependent on physical than psychological effort, which may explain the association between autonomy indoors and disease severity. A previous study similarly found that walking ability was associated only with the IPA autonomy indoors domain (Ryan et al. 2018). The EDSS is widely used to assess disease severity. However, it has been found to be much more closely linked to physical, especially walking, ability, than to psychological or cognitive abilities/problems (Cohen et al. 2012). This may explain the findings of a previous study showing that participation restriction measured with the Community Integration Questionnaire increases along with disease severity. The same study also found a stronger association of cognitive disorders with participation restriction than with physical limitations, when assessed with the EDSS (Cattaneo et al. 2017). In addition to the role of cognitive disorders in participation restrictions (Hughes et al. 2015), it has been observed that the psychological impact of MS does not necessarily increase along with disease severity (Gray et al. 2009).

In clinical practice, it is worth considering the relationships between the three self-assessment measures (IPA, WHOQOL-BREF and MSIS-29) when choosing the most appropriate measure for a specific situation, and thereby decreasing the burden which answering many different self-assessment measures may impose on the client. If the focus of the evaluation is on participation, the IPA merits consideration as it focuses on everyday activities rather than underlying elements such as muscle stiffness, problems of concentration or feelings of depression.

6.4 Changes in participation in everyday activities during the two-year multidisciplinary rehabilitation

The performance of everyday activities of moderately and severely disabled people with MS improved during the two-year multidisciplinary out-patient rehabilitation program. The multidisciplinary rehabilitation program, covering four themes (body control, mood, energy conservation, cognition), improved the functional needs of both those with moderate and those with severe MS. However, no difference in the size of the improvement was observed between these two groups. These findings show that improvement in participation in everyday activities is not solely dependent on disease severity.

Satisfaction with everyday activities improved equally in both groups from the beginning to the middle of the rehabilitation program. However, the performance of everyday activities in the moderate disability group improved at the same rate throughout the rehabilitation program. In contrast, the improvement in the performance of everyday activities of the severe disability group improved statistically significantly during the second year. This trend shows that performance itself and satisfaction with performance does not necessarily improve at the same rate. It could be argued that the rehabilitation process and change start with the identification of a challenging activity. The motivation to deal with the challenging activity increases over time as person acquires tools for change during the rehabilitation and the feelings of mastery and satisfaction with the change increase. This is consistent with the idea that personally meaningful goals related to everyday life lead to improved motivation and changes in behaviour (McPherson et al. 2015). In addition, the results underline the importance of setting a rehabilitation goal related to improving participation in the advanced as well as earlier stages of MS.

Clinically relevant changes have been determined to be 1.4 for the COPM Performance score and 1.9 for the COPM Satisfaction score (Eyssen et al. 2011a). In this study, more than half of the participants did not reach the clinically relevant change threshold scores for COPM Performance or Satisfaction. However, it is noteworthy that 44 % of participants clinically improved their performance and 39 % reported satisfaction with their performance in spite of the degenerative and non-predictive nature of MS.

The need for the evaluation of multidisciplinary programs has been highlighted in a recent review of systematic reviews of rehabilitation for people with MS (Khan & Amatya 2017). The need for evaluation of the effectiveness of a multidisciplinary rehabilitation over a longer period has also been emphasized (Khan et al. 2007). The present study adds knowledge on the impact of a long-lasting, out-patient multidisciplinary rehabilitation for improving participation in everyday activities. In particular, it shows that for people with severe disability to improve their performance of everyday activities requires a sufficiently long period of rehabilitation.

The present rehabilitation program is unique in that it combined a multidisciplinary approach with different themes and was implemented in an out-patient setting. Group sessions on different themes were also conducted with various combinations of different professionals. Therefore, comparing the findings of this study to those of recent multidisciplinary programs which have not used participation in daily life as an outcome measure and have been implemented in in-patient settings (Salhofer-Polanyi et al. 2013, Boesen et al. 2018) is difficult. However, one earlier study focused on a rehabilitation program targeting a single theme, fatigue, using participation in daily life as an outcome measure. The fatigue program showed clinically meaningful improvements in COPM performance and satisfaction with desired everyday activities for mildly or moderately disabled people with MS (Kos et al. 2016).

In clinical practice, rehabilitation professionals should carefully evaluate the client's needs of participation in everyday life and factors that might facilitate or hinder change. If the problems and facilitators and/or barriers in participation appear to be multifaceted, a multidisciplinary rehabilitation program resembling present program could be the right choice. In this case, the client will receive diverse knowledge and tools from a multidisciplinary professional group and peers that support the process of change in a complex situation. However, if the problem in participation is more unambiguous and/or the facilitators and/or barriers are more clear-cut, a more focused and shorter or intensive program might be more appropriate.

6.5 Self-reported reasons for changes in activities

Although the self-reported reasons for changes in daily activities were diverse, environmental factors were important in explaining these changes during the multi-professional group rehabilitation. Previous studies have highlighted the need for better understanding the connections between environmental factors and participation (Noreau & Boschen 2010, Garcia et al. 2015, Hammel et al. 2015, Magasi et al. 2015, Heinemann et al. 2016). Environmental factors impact dynamically, either positively or negatively, on participation on the societal (macro), community (mesa) or personal (micro) level. Typically, rehabilitation interventions focus on environmental factors on the micro level, that is, in the person's immediate physical or social environment, and hence the mesa or macro levels are not included in the intervention (Hammel et al. 2015). The present findings contribute knowledge on environmental factors which are essential facilitators or barriers to participation.

Physical environmental facilitators and barriers are the most commonly identified environmental factors. For example, assistive devices have been shown to have an important role in enabling participation in everyday life (Carver et al. 2016). This entails consideration of the quality of the assistive device. To enhance participation in social roles and activities, a device should be repairable, easy to maintenance and reliable (Magasi et al. 2018). In addition, consideration should be given to how device works outside the home environment. It has been found that people with mobility impairment, even when they have an appropriate mobility aid, are less likely to leave home and take part in social activities if an appropriate bathroom is not available in the environment where the social activity takes place (Greiman et al. 2018). Moreover, as well as assistive devices and modifications in the home environment, aspects of the built environment in the neighbourhood, such as benches, lightning and traffic light timing, also influence participation (Eisenberg et al. 2017). Furthermore, uncontrollable components of the natural environment, such as weather (Hollingsworth & Gray 2010) and seasonal factors (Ripat et al. 2015, Borisoff et al. 2018) have effects on participation.

The findings of this study support the need to actively focus on, or at least notice, community- and society-level as well as personal level environmental factors. For example, environmental modifications or assistive devices, which can be classed as personal-level environmental factors, were the most common facilitators of participation. However, at the same time, lack of them was the most common barrier. Therefore, it can be argued that securing environmental modifications or obtaining assistive devices that facilitate participation is not just a personal-level issue. It is also a mesa- and macro-level issue; for example, it can be asked whether adequate resources exist for evaluating and acquiring modifications and devices needed by individuals in various environments and circumstances.

In this study, the most frequently reported social-environmental facilitators were personal assistance and assistance from the family. This highlights the importance of both formal and informal support in daily life. In addition to actions for people with MS, the multidisciplinary rehabilitation program also included sessions in which family members could take part. It can be argued that these sessions encouraged the family members of people with MS to provide support and for people with MS to ask for help in daily life. However, this study supports previous findings (Khan et al. 2007) that more knowledge on the role of informal carers in multidisciplinary rehabilitation programs is needed.

The subjective dimension of functioning was found to be an important factor in explaining changes in everyday activities. Learning to do things in new way and anticipating challenging situations are examples of the personal factors highlighted by people with MS as facilitators of improvement in their performance of daily activities. Motivation, coping, and action planning have been observed to have a significant role in intervention outcomes (Chiu et al. 2011). Similarly, perceived disability, and especially impairments in mental functioning, have also been found to contribute to quality of life (Wynia et al. 2009). Thus, self-awareness of functional status influences daily activities and participation (Goverover et al. 2009). First, identifying and then eliminating hindrances and promoting personal facilitating factors is essential at every stage of the rehabilitation process (Geyh et al. 2011, Hamed et al. 2012).

The ICF classification offers a biopsychosocial framework for identifying various factors that facilitate or hinder participation. Because MS is a progressive and unpredictable disease, the need to consider contextual factors that influence participation need special consideration. In addition to the ICF outcomes, the diversity of the reasons for change in participation found in this study highlights the importance of applying the Enablement Theory (Whyte 2014) and behaviour change theories, such as the Theory of Intentional Action Control (Gollwitzer & Sheeran 2006), as well as specific treatment theories to guide interventions. Moreover, the core elements of a client-centred approach, such as effective communication and a good professional-client partnership (Constand et al. 2014), ensure that a person's unique life situation and the various factors that may facilitate or hinder participation are taken into account during the intervention process.

6.6 Methodological considerations

A major strength of this study is that it emphasizes knowledge based on participants' personal experiences. In addition, the main outcome measures, the IPA and the COPM, are self-assessment measures which emphasize different aspects of participation in daily life. A special feature of the COPM is that the individuals concerned name the activities that they find both challenging and the most important for them at the time. Thus, it does not assess a pre-determined list of functions (Carswell et al. 2004). The IPA, in turn, is a questionnaire in which the areas of assessment are pre-defined, precluding individuals from raising issues not already contained in the questionnaire. However, the IPA viewpoint is unique in that it foregrounds the aspect of autonomy. It can, therefore, be concluded that these two self-assessment measures are complementary.

Both instruments have been applied in many rehabilitation studies. The COPM has been proved to be valid, reliable, clinically useful (Carswell et al. 2004) and sensitive enough to measure changes in activities of daily life from the dual perspective of performance and satisfaction (Eyssen et al. 2011a). The validity and reliability of the IPA for people with MS has been proven in three studies (Vazirinejad et al. 2003, Sibley et al. 2006, Vazirinejad et al. 2015). Moreover, study I found additional evidence on the validity and reliability of the IPA, especially for the people with MS. To increase the reliability of the assessments in this study, all the investigators who administered the COMP and the IPA at different time points followed the same assessment protocol as laid down in an assessment manual. They were also familiar with the theory and concepts underlying the assessment methods. In addition, the assessors were not involved in the delivery of the rehabilitation program.

Using self-assessment measures, such as the IPA, COMP, MSIS-29 and WHOQOL-BREF, may contribute to a broader understanding of the impacts of a multidisciplinary rehabilitation in persons with MS (Weldring & Smith 2013). Furthermore, self-assessment measures have found to increase overall care quality, as they ensure that care is focused on the issues of greatest personal importance to the client (Philpot et al. 2018). This is particularly crucial for people with MS owing to the great number of challenges they face and the great variation in the issues important to them as individuals.

Despite the strengths of the self-assessment measures used, they also have their weaknesses. The phenomenon known as "response shift" may have affected the results. Response shift is a cognitive appraisal process that occurs in a situation in which individuals' different internal standards, values or conceptualization of the concept being measured influence their self-evaluations. (Schwartz et al. 2007, Schwartz 2010). Three types of response shift have been identified: first, internal standards of participation may change over time or because of changes in the disease (recalibration); second, values may change (reprioritization); and third, the person may conceptualize the target construct differently over time (reconceptualization) (Schwartz et al. 2018).

During the present two-year rehabilitation program, the life situation of the MS participants changed and in some cases the activities in focus lost their importance. It is noteworthy that approximately 10% of the activities were removed from the analyses at 12 months and at 21 months. All these deletions were carefully considered and only obviously meaningless activities were removed. For example, walking a dog was no longer relevant after the death of the dog.

The composition of the sample investigated in this study affects the generalizability of the findings. Over two-thirds of the participants were women. However, the same gender distribution has been observed in other prevalence studies (Ahlgren et al. 2011). All the study participants were Finns, a factor that may disallow generalizing the results to other cultures and populations. Moreover, the sample mostly comprised persons with moderate or severe disability. This may have influenced individuals' experiences of participation and the way they answered questions. For example, most of the participants were on a disability pension, a situation that may have influenced what activities are perceived as a challenge. In addition, the inclusion criteria for the study may have affected the results. Participants had to have restricted functioning in at least two of the following four domains: cognition, mood, fatigue and body control. Moreover, the results may have been influenced by the inclusion criterion of motivation to participate in the rehabilitation program.

In studies I and III the sample yielded narrower data. Because the majority of the participants were on a disability pension (83%), the IPA work and education opportunities domain was answered by only a small group of participants and hence was excluded from the structural equation models. However, at the same time, this target group can be argued to be adequate. A large proportion of people with MS retire prematurely: half of the people aged below 63 in EDSS groups 3.0 and 4.0, and 73% and 84% those in EDSS groups 5.0 and 6.0, respectively, had retired prematurely (Ruutiainen et al. 2016). There is, therefore, a need, using a valid tool, to describe and adequately support the participation of people with MS who are not in working life.

Although the recommendations on sample size vary (MacCallum et al. 1999), the number of people with MS in study I was small in relation to the number of parameters estimated. A larger cohort of patients with minor to severe disability and with fewer prematurely retired patients would have increased the generalizability of the findings.

The results of study I might have been influenced by a winter seasonal effect, especially among wheel-chair users (Lindsay & Yantzi 2014, Ripat et al. 2015, Borisoff et al. 2018). In addition to winter-related mobility challenges, sensitivity to heat, which is a common symptom of MS, may affect functioning in the summer time (Flensner et al. 2011). Therefore, the time at which the assessments were performed, late summer, could have influenced the activities that participants reported as challenging. However, in general, the participants highlighted typical winter-related activities such as snow clearing or walking on icy ground.

A strength of the multidisciplinary group-based intervention was the use of a client-centered approach and measures of individuals' personal experiences of changes in their performance of and satisfaction with the activities in daily life in which they wanted to improve. Moreover, the present intervention was exceptionally long compared with most of those previously studied.

The intervention was implemented according to a manual, produced beforehand and based on the available research evidence, for each theme (cognition, mood, fatigue, body control). However, because of the different combinations of participating professionals some variation is possible in how the themes were dealt with. Although the rehabilitation program was group-based, the rehabilitation content varied greatly across the participants. All participants attended 20 three-hour sessions and four whole-day sessions during the 21-month rehabilitation program. In addition to these sessions, three to five home visits were made based on the needs of the participant and networking done with other service-providers. The intervention sessions could comprise two long-version themes (chosen from the four themes of cognition, mood, fatigue, body control), such as cognition in the first year and fatigue in the second year. Alternatively, the participant could have opted for a short version of each of the four themes. The individual goals of the group members may also have influenced the emphasis in the sessions.

This variability in the implementation of the rehabilitation program, which is mainly based on the different needs of the participants, can also be seen as a strength as well as a weakness. It can be speculated that positive outcomes occurred either despite or because of the variability. One possible explanation is that the core elements of the rehabilitation program – group-based, long duration, multidisciplinarity, theme-based using participants' own goals – provided a structured frame in which it was possible to vary the content and implement client-centered rehabilitation. However, the wide variation in content renders it difficult to generalize and transfer the program to other contexts. It has been acknowledged that complex interventions, such as multidisciplinary rehabilitation programs for people with chronic progressive conditions, are difficult to study. Addressing the effectiveness of individually tailored rehabilitation programs was also found to be especially problematic in a previous systematic review on the effectiveness of multidisciplinary rehabilitations for people with MS (Khan et al. 2007).

This dissertation research applied a multimethod design incorporating both quantitative and qualitative data and analytical methods. However, this does not mean that it can be classified as a mixed method design, since it did not integrate methods or data to answer a single research question (Creswell & Plano Clark 2018). The multi-methodology enabled a focus on different kinds of research questions. Thus, it was possible to gain a more holistic picture of the complex and multifaceted phenomenon of the daily life activities and participation of people with MS. In study IV, especially, the qualitative data on perceived improvement increased understanding on the outcomes of the rehabilitation program. These findings support the value of taking a multifaceted view of the outcomes of rehabilitation for persons with MS and encourage careful investigation of the factors that facilitate or hamper participation in everyday life.

Theory-driven content analysis was applied in the qualitative data analysis of studies II and IV. Several strategies were applied to verify the trustworthiness of the data analysis. In recent years, the ICF has been used in a numerous studies as a tool for describing, comparing and contrasting information yielded by from different measures (Fayed et al. 2011). In this thesis, the commonly used linking rules (Cieza et al. 2002, Cieza et al. 2005) were applied to verify the linking process. However, following the linking protocol is not enough to guarantee the quality of the analysis. Hence, the quality of the analysis was also supported by investigator triangulation, that is, by cross-checking and verifying the interpretations of the data (Thurmond 2001). The linking process also had its limitations. The two researchers who linked the reported problems to the ICF categories were occupational therapists. Other health professionals might have made different decisions. In addition, had the judgments been made totally independently, the Kappa statistics for agreement (Cohen 1960) could have been used. However, the consensus-reaching process, with rigorous argumentation was chosen as both researchers were familiar with the data and had discussed it before starting the linking process.

Quantitative data were analyzed using various methods. Repeated measures of analysis of variance (RM-ANOVA) was used to analyze differences between the groups, and the assumption of sphericity was confirmed using Mauchly's test. In studies I and III, Structural equation modeling (SEM), specifically Confirmatory factor analysis (CFA) in study I, was applied using Mplus Version 6.12 (Muthén & Muthén 2010). The assumptions of these different analysis methods were confirmed.

CFA was considered an appropriate method for testing the IPA construct of perceived participation and autonomy. This construct seems to be multidimensional, although the factors strongly correlated with each other. If the purpose of the study had been to measure the unidimensionality of the IPA, as has been done in a few former studies (Kersten et al. 2007, Lund et al. 2007, Fallahpour et al. 2011), Rasch analysis would have been a more appropriate method. However, analysis of the results of the study using the Persian version of the IPA (Fallahpour et al. 2011) supported two different constructs: performance-based participation, comprising 19 items of the autonomy indoors, family role and autonomy outdoors domains, and social-based participation comprising 7 items from the social relationships domain. In addition to that finding, two other studies have shown that the IPA is a multidimensional construct with correlated factors (Cardol et al. 2001, Sibley et al. 2006). Therefore, CFA was applied in this study to confirm the factor structure of the Finnish version of the IPA. Moreover, it has been proposed that in clinical practice the domain scores might provide the knowledge required to focus a projected rehabilitation program (Kersten et al. 2007). Research, applying Rasch analysis, on the unidimensionality of each domain of the Finnish version of the IPA has been done in e.g. comparing the Dutch and English versions of the IPA (Kersten et al. 2007). This is needed, as the IPA autonomy outdoor domain has been used separately in a clinical study (Rantakokko et al. 2016).

SEM was considered an appropriate method in study III for testing a model in which several factors were hypothesized as predictors of participation and autonomy. It has been shown that participation is a complex phenomenon which is hard to conceptualize (Dijkers 2010, Babulal et al. 2015, van de Velde et al. 2018). The strength of the SEM performed in this study was that it yielded a model in which participation was predicted by a combination of different factors, thereby retaining and also explaining the true complexity of the phenomenon. However, this study was unable to show causal relationships, as this would require a different study design, such as a before-and-after design.

6.7 Implications and suggestions for future research

The results of this dissertation research show that self-assessment measures can contribute to a broader understanding of the participation restrictions experienced in daily life by people with MS. Self-assessment measures capture perceived challenges in everyday life and reveal what factors influence these challenges. In clinical practice, it should be carefully considered which self-assessment measures provide the most relevant information in a specific situation, and the psychometric properties of the measures chosen should then be ascertained. The findings of this study suggest that the combination of two different kinds of self-assessment measures, in this case the Canadian Occupational Performance Measure and the Impact on Participation and Autonomy instrument, can provide a broader and deeper understanding than one measure alone of the participation of people with MS.

The results showed that the two-year multidisciplinary group-based out-patient rehabilitation program improved performance and satisfaction with the activities of daily life of people with MS. Given the progressive and unpredictable nature of the disease, this is a notable finding. However, it revealed that to induce changes in the performance of daily activities requires a lengthy rehabilitation program. The improvement seemed to occur either during the second year or at a constant rate during both years of rehabilitation. The fact that people with MS may perceive problems in all types of daily activities has to be considered during a multidisciplinary rehabilitation. It can be argued, that a group-based rehabilitation program, including different elements such as theme-based sessions with peer support, home-visits and sessions for loved-ones, supports the constantly changing and individually varied daily life of people with MS (Månsson Lexell et al. 2006, Lexell et al. 2009, Lexell et al. 2014). Moreover, the environmental factors affecting perceived participation and autonomy should be considered when planning interventions to promote participation and autonomy.

Signs were found that disease severity has some influence on how people with MS experience challenges in participation in daily life and on the trend to improvement in the performance of activities of everyday life. However, the findings of this study also indicated wide variation in participants' experiences of problems in daily life and also in non-disease-related factors that help in performing daily activities. Hence, disease severity alone should not guide the rehabilitation process. For example, disease severity predicted perceived participation and autonomy in indoor activities, yet the associations between the other dimensions of participation and autonomy and disease severity were weak. These findings suggest that clinical assessment methods should include instruments such as the COPM that foreground the subjective variability and complexity of daily activities. In addition, experiences in all the dimensions of participation and autonomy were closely associated with perceived quality of life and the impact of the disease, and hence it would be useful to assess participation and autonomy and plan interventions based on this information. The IPA seems to be an appropriate measure for these purposes.

Complexity and variation in experiences were found also in the reasons for change reported by the participants in the group rehabilitation. This should encourage both clinicians and people with MS to identify which factors affect participation and which are relevant changes for each person. The ICF comprehensive and brief core sets are appropriate tools to capture challenges to participation in everyday life. The use of a core set, especially, has been argued to expand the assessment beyond the traditional biomedical aspects of the individual to include relevant environmental factors (Camargo 2018). At the same time, it is worth remembering that assessments should not be limited to the issues included in core sets (Camargo 2018).

The results of this dissertation research also support previous studies and theories according to which participation is an even more complex phenomenon than the ICF definition suggests. It is, therefore, recommended that knowledge gained from other theories which explain participation from the viewpoint of the individual and connect the values, meanings, interests, motivation and perceived self-efficacy of the individual to participation in such areas as occupational balance and well-being (Backman 2010, Wagman et al. 2012, Wagman et al. 2015) and occupational engagement (Polatajko et al. 2007, Kennedy & Davis 2017, Fisher & Marterella 2019) is also applied. The present findings should encourage the examination of autonomy as an aspect of participation in people with chronic and degenerative conditions such as multiple sclerosis.

The results of this thesis indicate further research needs. The validation of the ICF categories in the Activities and participation component included in the core sets for MS should be validated with a more representative sample of people with MS. The COPM has not been used before to validate the ICF core sets. The perspective of people with disabilities has been studied using interviews with both an open and ICF-based approach (Stamm et al. 2005, Coenen et al. 2006) and with focus groups (Hieblinger et al. 2009). The suitability of the Finnish version of the IPA for assessing change over time and identifying clinically important changes following a rehabilitation intervention for persons with minor disability and other diagnoses should also be evaluated.

The role of environmental factors - physical, psychological, economic, societal and social – in the participation in daily life of persons with MS needs to be understood in greater detail. We need a better understanding of the different types of environmental interventions that might, despite the degenerative nature of the disease, improve the participation in daily life, and especially autonomy, of people with MS. In this study, the associations between severity of cognitive impairment and participation were not investigated. However, previous studies have shown that cognitive problems are associated with participation (Hughes et al. 2015, Plow et al. 2015, Cattaneo et al. 2017). Therefore, both in clinical practice and future research, it is recommended that, besides the factors found in this study, consideration is given to the effect on participation of cognitive problems and other invisible challenges.

The large number of factors in the multidisciplinary rehabilitation program caused variation in the implementation of the program. Therefore, further research is needed on which combinations of the four themes (cognition, mood, fatigue, body control) show the best improvements for which subgroups. In addition, it would be important to study combinations of treatment methods such as information, guided training in groups, individualized home training programs, peer support groups and environmental modifications. These were all applied in the group rehabilitation process, but their individual influences were not studied in detail. As the previous review of multidisciplinary rehabilitation for MS suggests, the need remains to study the optimal number, duration and intensity of treatment sessions (Khan et al. 2007).

7 MAIN FINDINGS AND CONCLUSIONS

The main findings of this dissertation can be summarized as follows:

1. The construct validity and reliability of the Finnish version of the Impact on Participation and Autonomy, with four perceived participation restriction domains as a measure to capture autonomy in the participation of people with MS, were confirmed.
2. Perceived problems of participation in daily life of people with MS supported the ICF comprehensive and brief core sets for MS. The role of recreation and leisure should be considered when further developing the brief ICF core sets for MS.
3. Perceived participation in daily life showed little variation between moderately and severely disabled people with MS.
4. Participation was predicted by quality of life and the psychological and physical impacts of the disease. Disease severity alone did not predict restrictions in participation.
5. The two-year multidisciplinary group-based out-patient rehabilitation program covering four themes (body control, mood, energy conservation and cognition) improved perceived performance and satisfaction with everyday activities in people with both moderate and severe MS.
6. Self-reported reasons for the change during the rehabilitation program were diverse. Personal and environmental factors had a major role.

In conclusion, the results of this dissertation research indicate that participation in everyday life is a complex phenomenon which is affected by multiple factors. It is recommended, therefore, that participation is measured with self-assessment instruments. In addition, it is recommendable consider the fit between the content of the instrument and what the individuals it is administered to consider important. Both the IPA and the COPM outcomes testified to the wide variation in perceived challenges to participation and activities in everyday life in persons with MS. Moreover, the findings suggest that a multidisciplinary theme-based group rehabilitation based on rehabilitees' individual needs and goals has positive impacts on performance and satisfaction with daily activities. However, to induce changes in performance and satisfaction in daily activities requires long-term rehabilitation that takes both personal and environmental factors into account. To fully evaluate the effectiveness of multidisciplinary long-term rehabilitation programs for people with MS, more studies with randomized controlled trial designs are needed.

YHTEENVETO (SUMMARY IN FINNISH)

MS-tautia sairastavan henkilön osallistuminen arjen toimintaan

Multippeliskleroosi (MS) on etenevä ja ennustamaton sairaus, joka aiheuttaa MS-tautia sairastaville monenlaisia haasteita arkielämän toimintoihin ja osallistumiseen. MS-tautia sairastavan henkilön kokemien arjen haasteiden selvittäminen on välttämätöntä, jotta kuntoutuksella voidaan tukea tarkoituksenmukaisella tavalla arjessa toimimista. Perinteisesti toimintakyvyn arvioinnissa on painotettu objektiivisten, ja usein ruumiin ja kehon rakenteiden sekä kehon toimintojen arviointiin kohdentuvien, arviointimenetelmien käyttöä. Kuitenkin kuntoutuksen päämääränä on viime kädessä osallistumisen vahvistaminen elämän eri alueilla. Tämän vuoksi henkilön oma kokemus osallistumisestaan arkeen ja eri toimintojen yksilöllisten merkitysten selvittäminen on nostettu objektiivisten tiedonkeruun menetelmien rinnalle. Erityisen tarpeellista henkilön oman kokemuksen selvittäminen on silloin, kun henkilöllä on toimintarajoitteita aiheuttava krooninen tai etenevä sairaus kuten MS.

Osallistuminen arjen elämään on monimutkainen ilmiö, johon vaikuttavat useat tekijät. Kansainvälisessä toimintakyvyn, toimintarajoitteiden ja terveyden (ICF) luokituksessa osallistuminen on määritelty osallisuudeksi elämän tilanteisiin. ICF-luokituksen ohella osallistumista on tarkasteltu useissa tutkimuksissa laajentaen ja syventäen ilmiötä muun muassa kontekstuaalisten tekijöiden, sosiaalisen tai yhteisöllisen osallistumisen, subjektiivisen kokemuksen, autonomian ja arjen toiminnan näkökulmista.

Osallistumisen arviointimenetelmissä osallistuminen on käsitteellistetty ja operationalisoitu eri tavoin. Arviointimenetelmät eroavat toisistaan myös siinä mittaavatko ne objektiivista vai subjektiivista osallistumista ja ovatko ne yksi- vai moniulotteisia. Lisäksi arviointimenetelmien kehittämisprosesseissa ja psykometrisissä ominaisuuksissa on eroa. Näiden eroavaisuuksien vuoksi arviointimenetelmän valintaa on tarpeen harkita kulloisenkin asiakasryhmän ja kunkin henkilön yksilöllisen tilanteen mukaisesti käyttäen hyväksi tutkimustietoa. Arjen toiminnan ja osallistumisen haasteiden ja niihin vaikuttavien tekijöiden monimuotoisuuden vuoksi MS-tautia sairastavat hyötyvät monialaisesta kuntoutuksesta. Kliinistä työtä tukevia tutkimuksia monialaisten, ja etenkin pitkäkestoisten, kuntoutusohjelmien vaikutuksista ja vaikutuksia edistävistä tekijöistä on vielä rajallisesti.

Tämän väitöskirjatutkimuksen tavoitteena oli tutkia Valinnat ja osallistuminen jokapäiväiseen elämään –kyselyn (Impact on Participation and Autonomy questionnaire) eli IPA-kyselyn suomenkielisen version pätevyyttä, kartoittaa MS-tautia sairastavien havaitsemia osallistumisen ja arkipäivän toimintojen rajoituksia, selvittää osallistumiseen yhteydessä olevia tekijöitä sekä arvioida kaksivuotisen monialaisen ryhmäkuntoutuksen vaikutuksia MS-tautia sairastavien arjen toimintoihin niillä henkilöillä, joilla sairaus vaikutti huomattavasti toimintakykyyn Expanded Disability Status Scale (EDSS) -mittarilla arvioituna.

Väitöskirja perustuu MS-tautia sairastavien (n = 113) monialaisen ryhmäkuntoutusprojektin aineistoon ja lisäaineistoon (n = 89), joka kerättiin suomenkielisen IPA-kyselyn psykometrisien ominaisuuksien arvioimiseksi. IPA-kyselylomakkeen rakennevaliditeettia tutkittiin konfirmatorisella faktorianalyysillä ja osallistumista ennustavia tekijöitä rakenneyhtälön mallinnuksella. Osallistumista ja arkielämän toimintoja tutkittiin kahdella itsearviointimenetelmällä: IPA-kyselylomakkeella ja Canadian Occupational Performance Measure (COPM) haastattelumenetelmällä. Aineistojen analyysissä hyödynnettiin ICF-luokitusta. Kaksivuotisen monialaisen ryhmäkuntoutuksen aikana tapahtuvaa edistymistä arjen toiminnoissa arvioitiin COPM-menetelmällä. Keskivaikeaa ja vaikeaa MS-tautia sairastavien henkilöiden edistymisen vertailussa käytettiin toistomittausten varianssianalyysiä.

Konfirmatorinen faktorianalyysi vahvisti IPA-rakenteen joka sisältää neljä osa-aluetta (autonomia sisällä, rooli perheessä, autonomia ulkona sekä sosiaalinen elämä ja suhteet). Työ ja koulutus –osa-alue jätettiin analyysin ulkopuolelle, koska vain pieni osa osallistujista vastasi kysymyksiin. IPA-kyselyä voi sisäisen rakenteensa osalta pitää pätevänä menetelmänä mittaamaan koettua osallistumista autonomian näkökulmasta MS-tautia sairastaville henkilöillä, joilla sairaus aiheuttaa keskivaikeita tai vaikeita toimintarajoitteita. IPA-kysely tuo esille, millä osallistumisen alueella henkilö kaipaa enemmän tukea, ja tämän pohjalta voidaan kohdentaa kuntoutustoimenpiteitä. Osa-alueiden tarkastelun lisäksi on suositeltavaa tarkastella myös yksittäisten kysymysten antamaa tietoa osallistumisesta, jotta tukea voi edelleen kohdentaa tarkemmin.

Kahdella erilaisella arjen toiminnan ja osallistumisen itsearviointimenetelmällä (IPA ja COPM) kerätty aineisto tukee aiempien tutkimusten tuloksia siitä, että MS-tautia sairastavat kohtaavat arjessa monia haasteita ja nämä haasteet vaihtelevat suuresti henkilöiden välillä. Tämän väitöstutkimuksen tulosten perusteella IPA ja COPM ovat luotettavia arviointimenetelmiä, joilla on mahdollista saada esille MS-tautia sairastavien oma kokemus arjen toimintojen ja osallistumisen haasteista ja niiden monimuotoisuudesta. Arjen toimintojen ja osallistumisen haasteet erosivat hyvin vähäisesti verratessa henkilöitä, joilla oli Expanded Disability Status Scale (EDSS) –skaalan perusteella luokiteltuna keskivaikeita tai vaikeita toimintarajoitteita. Kummassakin ryhmässä koettiin arjen toiminnan ja osallistumisen olevan rajoittunutta kotitöihin osallistumisessa ja vapaa-ajan toiminnoissa kuten ystävien luona vierailuissa tai matkustamisessa sekä työelämään osallistumisessa. Lisäksi tulokset MS-tautia sairastavien kokemista osallistumisen ja toiminnan ongelmista validoivat ICF-luokituksen MS-taudin laajan ja lyhyen ydinlistojen suoritukset ja osallistuminen –alueen listan.

Rakenneyhtälömallin tulokset osoittivat, että elämänlaatu mitattuna Maailman terveysjärjestön elämänlaatumittarin lyhyellä versiolla (WHOQOL-BREF) sekä sairauden koetut psyykkiset ja fyysiset vaikutukset mitattuna Multiple Sclerosis Impact Scale (MSIS-29) -mittarilla ovat yhteyksissä osallistumisen ja autonomian kokemukseen. Lisäksi sairauden vaikeusaste oli yhteyksissä osallistumisen autonomia sisällä –osa-alueeseen.

Kaksivuotinen monialainen ryhmäkuntoutus edisti sekä keskivaikeita että vaikeita toimintarajoitteita omaavien MS-tautia sairastavien henkilöiden toiminnoista suoriutumista ja tyytyväisyyttä. Monialainen kuntoutusohjelma, joka keskittyy neljään MS-taudin kannalta tärkeään teemaan, kehon hallintaan, mielialaan, energian säästämiseen sekä kognitioon, onnistui vastaamaan arjen toiminnan haasteisiin. Kuntoutusohjelman aikana tapahtuneet itse ilmoitetut muutoksen syyt olivat moninaiset. Useimmin henkilöt ilmoittivat muutosten syiksi ICF-luokituksen yksilö- ja ympäristötekijät.

Yhteenvetona tulokset nostavat esille MS-tautia sairastavien osallistumiseen liittyvien kokemusten ja toimintojen moninaisuuden arjen elämässä. Nämä kokemukset eivät ole selitettävissä sairauden vaikeusasteella. Tämän vuoksi on suositeltavaa käyttää itsearviointimenetelmiä MS-tautia sairastavien osallistumisen ja arjen toiminnan kokemusten esille saamiseksi. MS-tautia sairastavien henkilöiden yksilöllisiin tarpeisiin ja tavoitteisiin perustuvalla monialaisella, teemoihin perustuvalla ryhmäkuntoutuksella on myönteisiä vaikutuksia suoritukseen ja tyytyväisyyteen päivittäiseen toimintaan. Muutokset vaativat kuitenkin pitkäaikaista kuntoutusta, jossa otetaan huomioon sekä yksilölliset että ympäristötekijät. Arkielämän toimintoja ja osallistumista tukevien monialaisten ja pitkäkestoisten kuntoutusohjelmien vaikutusten arvioimiseksi tarvitaan edelleen lisää tutkimuksia satunnaistetuilla kontrolloiduilla tutkimussuunnitelmilla sekä monimenetelmällisiä tutkimuksia, joilla voidaan todentaa muutosta edistävät ja estävät yksilöön ja kontekstiin liittyvät tekijät.

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ORIGINAL PAPERS

I

PSYCHOMETRIC EVALUATION OF THE FINNISH VERSION OF THE IMPACT ON PARTICIPATION AND AUTONOMY QUESTIONNAIRE IN PERSONS WITH MULTIPLE SCLEROSIS

by

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Psychometric evaluation of the Finnish version of the Impact on Participation and Autonomy questionnaire in persons with multiple sclerosis

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Psychometric evaluation of the Finnish version of the Impact on Participation and Autonomy questionnaire in persons with multiple sclerosis

Abstract

Objective: The objective of this study was to evaluate the psychometric properties of the Impact on Participation and Autonomy (IPA) questionnaire. The Finnish version of IPA (IPAFin) was translated into Finnish using the protocol for linguistic validation for patient-reported outcomes instruments.

Methods: A total of 194 persons with multiple sclerosis (MS) (mean age 50 years SD 9, 72% female) with moderate to severe disability participated in this study. A confirmatory factor analysis (CFA) was used to confirm the four factor structure of the IPAFin. The Work and Educational Opportunities domain was excluded from analysis, because it was only applicable to 51 persons. Internal consistency was investigated by calculating Cronbach's alpha.

Results: CFA confirmed the construct validity of the IPA (Standardized Root Mean Square Residual = 0.06, Comparative Fit Index = 0.93, Tucker-Lewis Index = 0.93, Root Mean Square Error of Approximation = 0.06), indicating a good fit to the model. There was no difference in the models for females and males. Cronbach's alpha for the four domains ranged between 0.80 and 0.91, indicating good homogeneity.

Conclusion: The construct validity and reliability of the IPAFin is acceptable. IPAFin is a suitable measure of participation in persons with MS.

Keywords:

Assessment, autonomy, confirmatory factor analysis, multiple sclerosis, participation, rehabilitation

Introduction

Multiple Sclerosis (MS) is a degenerative and inflammatory autoimmune disease of the central nervous system with a disabling, progressive and unpredictable course (Compston & Coles 2008b). The estimated global number of persons with MS was 2.3 million in 2013 (Multiple Sclerosis International Federation 2015). Typical body function level impairments due to MS include fatigue, bladder dysfunction, sensory and motor symptoms such as impaired tactile perception, pain, muscle weakness, spasticity and poor walking balance (Holper, Lisa et al. 2010). MS also causes behavioural (Rosti-Otajärvi & Hämäläinen 2013) and cognitive problems (Langdon 2011). The impairments in body functions may impact activities and participation significantly.

Participation has been considered as an important outcome for rehabilitation (Cardol, M. et al. 2002) and especially for occupational therapy (Law, Mary 2002). However there is no consensus on the conceptualization of this complex phenomenon (Dijkers, M. P. 2010). Within the International Classification of Functioning, Disability and Health (ICF) participation restrictions are defined as experienced problems with involvement in life situations (World Health Organization 2001). There are interactions in the ways how the concept of participation is used in the models and theories of occupational therapy and in the ICF. In the Model of Human Occupation (MOHO) the concept occupational participation is contrasted with the concept of participation as defined in the ICF, and the occupational performance is used in the same meaning as activity in the ICF (Kramer, Bowyer & Kielhofner 2008). The key concepts of the Canadian Model of Occupational Performance and Engagement (CMOP-E) are occupational performance and engagement which are closely connected to the ICF participation (Polatajko et al. 2007). In the Person-Environment-Occupation model, occupational performance results from the dynamic relationship between the person, his/her occupations and roles, and the environments in which he/she lives, works and plays (Law, Mary et al. 1996). Participation can be viewed as the lived experience, which is influenced by the person, activity and environment and their mutual interaction (Mallinson & Hammel 2010b). Participation may be affected by environmental factors, and correspondingly, better participation on an individual level may enable individuals contribute to environmental factors that restrict participation. (Piškur 2014). These aspects are common in all the above mentioned occupational therapy models and ICF although there is some variation in how the participation is defined. In this article, participation is understood as an involvement in both activities of daily living (ADL) and social activities not excluding a situation in which a person can be autonomous to some extent or able to control his/her own life, although he/she does not accomplish things independently by him/herself (Perenboom & Chorus 2003a).

The impact of MS on participation is considerable. (Einarsson et al. 2006). The experiences of restrictions in participation are individual and related to all aspects of daily life (Månsson Lexell, Iwarsson & Lexell 2006). The ability to perform satisfactorily with both primary ADL (P-ADL) and instrumental ADL (I-ADL) has been found to be hampered in persons with moderate to severe MS (Månsson & Lexell 2004). Therefore, both P-ADL and I-ADL should be evaluated (Månsson & Lexell 2004). Persons with MS experience that functional limitations have forced them to continuously struggle to maintain engagement and have made it necessary to construct a different life than before (Lexell, Eva Månsson, Lund & Iwarsson 2009). Moreover, the subjective experiences of problems encountered in everyday life vary considerably among persons with MS, for example, from ICF categories “moving around in different locations” or “washing oneself” to “doing housework” or ”recreation and leisure” (Karhula et al. 2013). There is an evident need to measure participation with a valid tool to understand the participation restrictions at the individual level and, thus, to better support persons with MS to participate despite these restrictions.

The Impact on Participation and Autonomy (IPA) questionnaire was developed in the Netherlands to measure participation from the individual’s point of view (Cardol, M., de Haan, van den Bos, G A, de Jong & de Groot 1999b). The IPA is a generic questionnaire which addresses perceived participation (Cardol, M. et al. 2001). In addition, the questionnaire addresses the concept of autonomy, as the developers found in their literature review that autonomy is a pre-requisite for effective participation, and therefore suggested that autonomy is the ultimate aim of rehabilitation (Cardol, Mieke, Jong & Ward 2002). The original Dutch version of the IPA was developed utilizing the results of the psychometric study as well as experts’ and rehabilitation consumers’ opinions and it consisted of 31 items (Cardol, M., de Haan, van den Bos, G A, de Jong & de Groot 1999b, Cardol, M. et al. 2001). In the final version of the IPA, the person answers altogether 41 itemss of which 32 concern the perceived participation and autonomy and nine concern the perceived problems with participation (Sibley et al. 2006b). For older people there is a modified version called IPA-O which includes 22 items (Hammar et al. 2014).

The IPA has been translated into a number of different languages including English, French, Persian and Swedish. Validation studies of the IPA have been conducted with the English (Cardol, M. et al. 2002, Sibley et al. 2006b), Swedish (Lund et al. 2007), French (Poulin & Desrosiers 2010) and Persian versions (Fallahpour et al. 2011). Furthermore, a comparison of the Dutch and English version has been conducted (Kersten et al. 2007). These studies addressed various dimensions of validity and they have been conducted with heterogeneous patient groups. Taken together, the different versions of the IPA have shown acceptable psychometric properties including construct validity and reliability.

Progressive disease influences how individuals experience restrictions in participation. A constantly changing function requires persons with MS to find and create new ways to participate in everyday life (Lexell, Eva Månsson, Lund & Iwarsson 2009).The progressive nature of the disease may also have an impact on measuring participation.

The psychometric properties of the IPA with persons with MS have been evaluated at least in two studies (Sibley et al. 2006b, Vazirinejad, R., Lilley & Ward 2003). Sixty persons with MS participated in the study of Sibley et al (Sibley et al. 2006b) but their results were not separately reported in terms of validity or reliability. The acceptability of the English version of the IPA was evaluated by 35 persons with MS who considered that from the items of the IPA the Mobility domain was the most relevant and the Education domain least important (Vazirinejad, R., Lilley & Ward 2003). The study did not evaluate the construct validity and reliability of the IPA (Vazirinejad, R., Lilley & Ward 2003).

There is no measure of participation and autonomy in Finnish. Since cultural issues may affect perceptions of participation and autonomy , there is a need to translate and validate IPA into Finnish language and with Persons with MS. The purpose of this study was to evaluate the psychometric properties of IPAFin the perceived participation and autonomy aspect with persons with MS. The perceived problems with participation scale has been found to only be sensitive enough to identify those who experience problems and those who do not (Lund et al. 2007). Therefore, using the perceived problems with participation scale instead of information from individual questions in clinical settings is questionable and it is not appropriate to evaluate the psychometric properties of the problems with participation scale. The study focused on evaluating the construct validity of the IPAFin the perceived participation and autonomy aspect with persons with MS by using a confirmatory factor analysis (CFA) framework and investigating the reliability of the individual IPAFin perceived participation and autonomy domains.

Material and methods

Design and data collection

Persons with MS were included by convenience sampling with pre-defined inclusion and exclusion criteria. The inclusion criteria were as follows: (i) age between 18 and 65 years (inclusive), (ii) a confirmed diagnosis of MS, (iii) ability to fill in questionnaires independently or with the help of an assistant. Participants were excluded if they were not capable of expressing their own choices or answering questions in the questionnaires. The data for this cross-sectional study was collected in two phases. First data set was collected in 2011 from persons with MS who participated in a two-year multi-professional, group-based out-patient rehabilitation project which was conducted by the Finnish NeuroSociety, the Finnish Social Insurance Institution and the GeroCenter Foundation for Aging Research and Development. Rehabilitation professionals from the Finnish NeuroSociety together with local health care professionals recruited participants from three areas of Finland (Helsinki, Kuopio and Turku) (Salminen et al. 2014).The second data set was collected from persons with MS in 2012–2013 during an in-patient rehabilitation period of 1-3 weeks at Masku Neurological Rehabilitation Center in order to receive a larger sample for the evaluation of validity and reliability of the IPA-Fin. All participants provided written informed, and the study was approved by the Ethics Committees of the Finnish Social Insurance Institution (data set 1) and the Hospital District of Southwest Finland (data set 2).

Assessment methods

The participants' sociodemographic characteristics, including gender, age, living conditions (alone or with others), employment status (disability pension or not) and the duration of the disease were derived from participants using a questionnaire tailored for the purpose. Disease course (relapsing-remitting, primary-progressive, secondary-progressive) was classified by a neurologist from patient records according to Lublin and Reingold (Lublin, F. D. & Reingold 1996)The same neurologist evaluated the severity of MS by using The Expanded Disability Status Scale (EDSS) (Kurtzke 1983). The EDSS score ranges in steps of 0.5 from 0 (no impairment) to 10 (death). In practice, the lower EDSS grades (0–3.5) are defined by the signs in a neurological examination, while grades 4.0 and above are largely dependent on ambulation and the use of the upper extremities (Kurtzke 1983).

The questions in the IPA are organized into nine areas (mobility, self-care, activities in and around the house, looking after one's money, leisure, social life and relationships, helping and supporting other people, paid or voluntary work, education and training) and in the end of the questionnaire there is the conclusive question of chances of living life the way one wants. The perceived participation and autonomy aspect is composed of the domains of Autonomy Indoors (7 items), Family Role (7 items), Autonomy Outdoors (5 items), Social Life and Relationships (7 items) and Work and Education Opportunities (6 items) (24). The nine items on the problems with participation in everyday life constitute the perceived problems with participation aspect and individual items provide important information, for example, for the rehabilitation goal setting (22). The respondent grades his/her perceived participation and autonomy for each item on a 5-point Likert-scale ranging from 0 (very good) to 4 (very poor) (Cardol, M. et al. 2001). A standardized mean score is calculated for each domain. The respondent also evaluates the problems with participation on nine subscales by rating a 3-point scale from 0 (no problem) to 2 (severe problems). Higher scores indicate lower sense of autonomy and more perceived participation restriction (Cardol, M. et al. 2001).

The IPA was translated into Finnish (IPAFin) using back-translation and expert-group consensus (Kanelisto & Salminen 2011). Permission to translate the IPA into Finnish and to publish it was received from the IPA author Mieke Cardol during 2010 (Kanelisto & Salminen 2011). The Finnish translation is based on the latest (Kersten et al. 2007) version of IPA that includes 32 questions on perceived participation and nine questions on the problems with participation. The protocol for linguistic validation of translated patient-reported outcomes instruments by Acquardo et al.(Acquadro 2004) was adopted and modified for the purposes of this translation process (Figure 1).
[Figure 1 near here]

Both the original Dutch IPA (Cardol, M. et al. 2001) and the English IPA-E (Sibley et al. 2006b, Kersten et al. 2007) were translated into Finnish by a trilingual rehabilitation expert who also compared both versions against each other. Additionally, the English IPA-E was translated into Finnish by an independent professional translator. A third person, who is a rehabilitation expert compared translations and made a proposal for the first Finnish version. This first version was discussed and reviewed in detail in the expert group that included four rehabilitation specialists. To ensure the conceptual equivalence the expert group made some changes that were related to the established Finnish rehabilitation terminology and the concept of autonomy. For example the first translation of the concept "disability" was understood too broadly in this context and therefore the translation was modified. Also the translation of the phrase "with or without aids or assistance" was clarified because in the first translation of the concept "assistance" was understood as "a professional who provides assistance". Therefore the translation of the phrase was modified.

The first version was piloted by a person with a neurological condition. This led to some clarifications in the layout of the questionnaire. Then the first version was used in the assessment of 116 persons with MS. The assessment was implemented as a structured interview that made it possible to collect information on the usability of the questionnaire. This led to minor changes in language and settings. Then, even after interviewing the 116 participants and making minor changes to the second Finnish version was back-translated into English by another professional translator to ensure the equality of the translation compared to the original English version of the IPA. The back-translation was analysed in the expert group, leading to some semantic changes in the Finnish version. For example the translation of the question "…to what extent does this cause you problems…" was modified. The Finnish language of the questionnaire was then revised by a professional, and finally checked by the expert group. The final third version, IPA-Fin, was accepted by the expert group in 2011.

Participants

Altogether 194 persons with MS (105 in data set 1 and 89 in data set 2) with considerable activity limitations (mean EDSS 6.0, SD 2) participated. Over two thirds of them were female, and the mean age was 50 (SD 9) years (Table 1).

Statistical Analysis

Confirmatory factor analysis (CFA) methods were applied to test the multidimensionality of the theoretical construct of the perceived participation and autonomy aspect of the IPAFin (Byrne 2013). CFA models were estimated and tested by using a statistical modelling program MPLUS 6.0 (Muthén & Muthén 2010). CFA consisted of the process which includes model specification, identification, estimation, testing fit, and re-specification (Kline 2015, Kelloway 2014). In the present study, analysis of the multidimensionality of the IPAFin was conducted in three phases including testing the original four-factor mode, the modified model, and models for women and men.

In the first phase of the analysis, CFA was specified as a four-factor model which includes four domains of IPAFin (Autonomy Indoors, Family Role, Autonomy Outdoors and Social Relationships domains) and 26 items. The Work and Educational Opportunities domain (6 items) was excluded from the CFA, because the items were only applicable to 51 persons. After the model specification, the identification of the model was examined. Basically, the model should be over-identified which means that the number of estimable parameters is less than the number of variances and covariances of the observed variables (Byrne 2013). There should be also at least three items for each factor (Kelloway 2014). The identified model was estimated using MPLUS which is designed to solve sets of structural equations (Kelloway 2014). The missing information is expected missing at random (MAR) and the method for estimation was the full information maximum likelihood method (FIML) (Kelloway 2014). Then the fit of the models was tested using several goodness-of-fit indices which produce different information about the model fit, that is, absolute fit, fit adjusting for model parsimony, and fit relative to a null model (Brown, T. A. 2006). Generally, it is recommended that each of these fit indices should be reported and considered, because they provide different information about the model fit (Bollen &

Long 1993). A statistically non-significant (p>0.05) chi-squared statistic means that the model does not significantly differ from the data. The standardized root mean square residual (SRMR) is the average discrepancy between the correlations observed in the input matrix and the correlations predicted by the model (Brown, T. A. 2006), and the good values of SRMR are close to 0.08 or below (Hu & Bentler 1999). The root mean square error of approximation (RMSEA) was used to assess the extent to which a model fits the population reasonably well (Brown, T. A. 2006). The values of RMSEA are good when they are close to 0.06 or below (Hu & Bentler 1999). The comparative fit index (CFI) and Tucker-Lewis index (TLI) values close to 0.95 or above indicate reasonable model fit (Hu & Bentler 1999). In addition, normalized residuals should be normally distributed, and there should not be over 5% of values which exceed the absolute value of over two.

In the second phase, if the original model does not fit to the data, the four-factor model will be re-specified. The model is modified according to the theoretically relevant modification indices of MPLUS 6.12.

Finally, in the third phase of the analysis, even though there were fewer men than women, the equality of the factor loadings and intercepts was tested. A model where the loadings were fixed equal and a model where the loading was estimated freely were compared with chi-square difference testing using the Satorra-Bentler scaled chi-square (Satorra & Bentler 2001). If the loadings were equal, the analysis was continued and compared to the model where intercepts were also constrained equal in and compared to the model in which only factor loadings were fixed equal (Brown, T. A. 2006).

The internal consistency of each five domain of IPAFin was considered good, if the Cronbach's alphas were greater than 0.8 (95% CI 0.7 and 0.9) (Streiner, Norman & Cairney 2014).

Results

Construct validity

The CFA model for perceived participation and autonomy aspect of IPAFin without modification (M1) showed that the theoretical model and the observed data did not fit well (Table 2). All other values of goodness-of-fit indices except the standardized root mean square residual (0.08) were unacceptable. Therefore, the model was modified according to the modification indices of MPLUS 6.12. The structure of the modified IPAFin four factor solution, factor loadings and modifications are presented in Figure 2. The items and standardized factor loadings are presented in Table 3. The theoretically relevant modifications are presented in Figure 2 and they were as follows: One item of the Family Role domain 3b "minor housework" and one item of the Autonomy Outdoors domain 1c "visiting friends" were loaded by the Autonomy Indoors domain, one item of the Family Role domain 4a "spending income" was loaded by the Autonomy Outdoors domain. Furthermore, 11 residual covariances were added (also presented in Figure 2). Five of the residual covariances were added between items of the Autonomy Indoors domain: 1a "getting around in one's own house were one wants" and 1b "getting around in one's house when one wants" (residual correlation 0.39), 1a "getting around in one's house where one wants" and 2a "getting washed and dressed the way one wishes" (0.19), 1b "getting around in one's when one wants" and 2e "eating and drinking when one wants" (-0.43), 2a "getting washed and dressed the way one wishes" and 2b "getting washed and dressed when one wants" (0.67), 2c "getting up and going to bed when one wants" and 2d "going to the toilet when one wishes and needs to" (0.44). In Family Role domain one residual covariance added between items 3c "getting heavy tasks done around the house" and 3d "getting housework done when one wants them done" (0.49). Also in Autonomy Outdoors domain were added one residual covariance between 1c "visiting relatives and friends when one wants" and 1d "going on the sort of trips and holidays one wants" (0.46). In Social Relationship altogether four residual covariances added between items: 6a "talking to people close to one on equal terms" and 6b "relationships with people who are close to one" (0.29), 6b "relationships with people who are close to one" and 6c "the respect from people who are close to one" (0.41), 6c "the respect from people who are close to one" and 6e "the respect one receives from acquaintances" (0.25) and in addition, 6d "one's relationships with acquaintances" and 6e "the respect one receives from acquaintances" (0.49).

[Figure 2 near here]

The indices for the model fit (Table 2) showed that the modified model fitted the data well according to all the other indices (CFI, TLI, RMSEA, SRMR) except chi-square. Moreover, normalized residuals were distributed as expected. The correlations between the factors were quite high, ranging from 0.48 (Autonomy Indoors and Social Relationships) to 0.86 (Autonomy Outdoors and Social Relationships).
The equality of the factor loadings and intercepts of the model between women and men was confirmed (Table 4).

Reliability

All domains had high levels of internal consistency, as determined by a Cronbach's alpha: 0.91 (Autonomy indoors), 0.88 (Family role), 0.88 (Autonomy outdoors) and

0.85 (Social relationships). The Cronbach's alpha for the IPA domain Work and education was 0.80, measured with a smaller sample (n=51).

Discussion

Construct validity and reliability of the IPAFin

The results of this study indicate that the construct of the perceived participation and autonomy aspect of the IPAFin consisting of Autonomy Indoors, Family Role, Autonomy Outdoors and Social Relationship domains is confirmed among persons with MS with moderate to severe disability. The Work and Education Opportunities domain was excluded from the analysis, because only a minority of the participants answered such questions. The results of the modified model support the four factor structure. Only the $\chi2$-value shows poor fit; all other fit indices show acceptable fit. However the $\chi2$-value considering the complexity of the model (degrees of freedom) is not high. According to Byrne (Byrne 1991) the $\chi2$ and degrees of freedom ratio values lower than two are considered to represent a minimally potential model fit. In addition, there were fewer than expected normalized residuals with an absolute value over two, and the residuals were distributed normally. Therefore, the model fit could be interpreted as sufficient.

Although the construction of the perceived participation aspect of the IPAFin was confirmed, in the modified model, three items were loaded in addition to the original main factor also to another theoretically relevant factor. Firstly, Item 1c "chances to visit relatives and friends when one wants" was loaded to the original main factor, the Autonomy Outdoors domain (0.55) and, in addition, to the other factor, the Autonomy Indoors domain (0.25). However, that did not disturb the model, because the loading to the main factor Autonomy Outdoors was clearly stronger. Secondly, Item 4a "spending income as wished", which is part of the Family Role domain, loaded more strongly to the Autonomy Outdoor domain (0.59) than to the Family Role domain (-0.01). The relation of Item 4a "the spending income as wished" to the Autonomy Outdoors domain can be interpreted as logical. It could be hypothesized that for most of the participants low income is a factor that affects them; for example, the items of the Autonomy Outdoors domain 1c "their chances to visit relatives and friends", 5a "their use of leisure time the way they desire" and 6g "their chances to see other people as often as they want" are all items that represent this fact. Thirdly, Item 3b "minor housework" loaded more strongly to the Autonomy Indoors domain (0.57) than to the Family Role domain (0.25). This could be explained by the demands of the activity. The demands of the activity Item 3b "chances of getting light tasks done around the house (e.g. making tea or coffee)" is closer to the activities of the Autonomy Indoors domain such as Item 2c "chances of getting up and going to bed" or Item 2e “chances of eating and drinking” than to the demands of activities of the Family Role domain, for example, Item 3a “chances of contributing to looking after my home”. These two, Item 4a “the spending income as wished” and Item 3b “chances of getting light tasks done around the house”, have also been considered in previous studies.

In the study by Sibley et al (Sibley et al. 2006b), the construction of the IPA was confirmed, although Item 4a ″spending income as wished″ loaded weakly (-0.12), as did Item 3b ″doing minor housework jobs the way one wants″ (0.25) to the Family Role domain. They did not show possible crossloadings of those items to any other factor than the main factor. The weak loading of Item 4a “spending income as wished” was explained by the fact that the subjects’ focus varied when they were answering the question; some were considering the physical capacity and others the ability to make decisions (15). In the two recent studies which used the Rasch model, Item 4a ″spending income as wished″ did not meet the goodness-of-fit criterion (Fallahpour et al. 2011, Lund et al. 2007). Fallahpour et al (Fallahpour et al. 2011) noticed that some respondents did not feel comfortable talking about financial issues with the researcher and that could have made answering unpredictable. Therefore, there is still a need to collect larger samples with a variety of clinical groups before excluding items from IPA or moving one IPA domain to another, especially when there are different kinds of explanations why an item does not load to the main factor. In clinical practice, it is important to consider the loadings of these two items in factors other than the main factor. Thus, if the persons with MS perceives restriction in the Autonomy Outdoors domain, there might also be restrictions in “spending income as wished” and, in the same way, if restrictions are perceived in the Autonomy Indoors domain, restrictions could also be perceived in “minor housework”. These should be considered when discussing the results of the IPA with a person with MS.

Seven correlations between residuals of the items were over 0.40. All of them were between items which loaded to the same factor. For example, in the Social Relations domain, residual correlation of items was high between Item 6b “relations with close people” and Item 6c “respect from close people” (0.41), and between Item 6d “relations with acquaintances” and Item 6e “respect from acquaintances” (0.49). In clinical settings, especially when participation restrictions appear in a certain domain, it is recommended that the answers to single items and the answers to similar items be considered when interpreting the results from different domains.

The ratio of females (72%) to males (28%) in this sample represents relatively well the overall gender distribution in MS (Compston & Coles 2008b). Therefore, a group comparison was conducted although the group of males was smaller than that of females. The preliminary finding of this study is that the IPAFin can be applied to both genders.

The evaluation of the reliability of the perceived participation and autonomy aspect of IPAFin was conducted with all five domains. Cronbach's alpha showed that the reliability of the IPAFin domains was acceptable.

Methodological considerations

CFA was considered an appropriate method to test the construct of the IPA perceived participation and autonomy aspect which seems to be a multidimensional construct, although the factors strongly correlated with each other. Highly correlated factors indicate that all domains measures the same underlying construct, perceived participation. Former studies (Lund et al. 2007, Kersten et al. 2007, Fallahpour et al. 2011) have used Rasch analysis to study the unidimensionality of the IPA perceived participation and autonomy aspect. In two studies, one conducted using the Swedish version of the IPA (Lund et al. 2007) and the other using both the Dutch and the English version (Kersten et al. 2007) unidimensionality was confirmed. However, the results of the study conducted using the Persian version of the IPA (Fallahpour et al. 2011) support two different constructs: performance-based participation including 19 items of Autonomy Indoors, Family Role and Autonomy Outdoors domains, and social-based participation including 7 items from the Social Relationships domain. Thus, there is evidence from this and former studies (Cardol, M. et al. 2001, Sibley et al. 2006b) that the IPA is a multidimensional construct with correlated factors. At the same time, the perceived participation and autonomy have been found to form a unidimensional construct (Lund et al. 2007, Kersten et al. 2007) or two unidimensional constructs (Fallahpour et al. 2011). However, as Kersten et al (Kersten et al. 2007) have discussed in their study, the scores of the domains instead of the score of the whole perceived participation restriction scale might give appropriate knowledge for clinical practice, as they support, for example, identifying the focus for rehabilitation. Therefore the aim of this study was to confirm the factor structure of IPAFin using CFA. The aim of the further research could be to study the unidimensionality of each domain for example with Rasch analysis. The Autonomy Outdoor domain has even been used separately from the whole IPA in a clinical study (Rantakokko et al. 2016). The systematic translation and cultural adaptation process of the measurement ensures that the results of the study are valid. The translation of the IPA Dutch and English to the Finnish language was conducted carefully according to the protocol for linguistic validation by Acquardo (35).

Limitations of the study

There are some limitations in our study. Firstly, the sample only included persons with moderate to severe disability as measured by EDSS (mean 6.0, SD 2), which limits the generalizability of the results to persons with MS with less limitations. Secondly, the severity of disease may affect how persons experience their participation and can also influence the way they answer the questions. Thirdly, the Work and Educational Opportunities domain was answered by only 51 persons, and the domain was thus excluded from the measure structure of the CFA. On the other hand, in a recent Finnish study on societal costs of MS, half of the persons in working age (aged below 63) in EDDS groups 3.0-4.0, as well as 73% and 84% of persons in EDSS groups 5.0 and 6.0, respectively, had retired prematurely (Ruutiainen et al, 2016). The majority of the participants in our study, like those in many international studies (20, 21, 27, 45), were on disability pension. Finally, although the recommendations for sample size vary (MacCallum et al. 1999), the number of persons with MS in our study was small with respect to the number of parameters estimated. A larger cohort of patients with minor to severe disability and with lower percentage of early retirement would have increased the generalizability of the findings.

Conclusion and clinical implication

In conclusion, the results of this study support the construction of the IPAFin with four perceived participation and autonomy domains. The internal structure of the IPAFin proved to be valid to measure perceived participation and autonomy in persons with MS with moderate to severe disability. IPAFin provides information on which areas of participation and autonomy need more support in the clinical practice of rehabilitation and occupational therapy. In light of these findings it is recommended to consider the individual's perceived participation both at domain and single item levels.

Further research is needed to examine the suitability of the IPAFin for persons with minor disability and other diagnoses. There is also a need to evaluate whether the IPAFin is an appropriate and sensitive enough measure for assessing the change over time or clinically important changes following a rehabilitation intervention.

Conflict of interest statement

The authors declare no conflict of interest.

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Table 1. Characteristics of the participants (n=194)

Mean /median age years (SD/ min–max)	50/51 (9/26-65)
Mean /median duration of disease years (SD/min–max)	15/14 (8/1-42)
Gender n (%)	
male	55 (28)
female	139 (72)
Living alone n (%)	63 (33)
Disability pension n (%)	161 (83)
Disease severity (EDSS) mean/median (SD / min–max)	6/6 (2/0-9)
mild 0–3.5 n (%)	8 (4)
moderate 4.0–5.5 n (%)	62 (32)
severe 6.0–8.5 n (%)	124 (64)
Disease subtype n (%)	
relapsing-remitting	64 (33)
primary-progressive	40 (20)
secondary-progressive	87 (45)
unknown	3 (2)
Data set 1, collected during out-patient rehabilitation n (%)	105 (54)
Data set 2, collected during short in-patient rehabilitation period n (%)	89 (46)

Table 2. Statistics for CFAs of IPAFin four factors with the original model (M1) and the modified model (M2)

Model	χ^2	df	$\chi2/df$	p-value	CFI	TLI	RMSEA	SRMR
M1	858.98	293	2.93	< 0.001	0.80	0.79	0.10	0.08
M2	467.28	279	1.67	< 0.001	0.93	0.93	0.06	0.06

M1 = Original four factor model without modifications

M2 = Four factor model with modifications (see modification in the figure 2)

$\chi2$ = Chi-squared statistic, df = Degrees of freedom, CFI = Comparative fit index, TLI = Tucker-Lewis index, RMSEA = Root mean square error of approximation, SRMR = Standardized root mean square residual

Table 3. Standardized factor loadings of the modified four factor model

Factor	Autonomy Indoors	Family Role	Autonomy Outdoors	Social Relationships
Items of the IPA				
1a getting around in one's house where one wants	.56			
1b getting around in one's house when one wants	.77			
2a getting washed and dressed the way one wishes	.71			
2b getting washed and dressed when one wants	.82			
2c getting up and going to bed when one wants	.79			
2d going to the toilet when one wishes and needs to	.79			
2e eating and drinking when one wants	.88			
3a contributing to looking after one's home		.78		
3b getting light tasks done around the house	.57*	.25		
3c getting heavy tasks done around the house		.74		
3d getting housework done when one wants it done		.78		
3e getting minor repairs and maintenance work done		.71		
3f fulfilling one's role at home as one would like		.82		
4a choosing how one spends one's own money		-.01	.59*	
1c visiting relatives and friends when one wants	.25*		.55	
1d going on the sort of trips and holidays one wants			.66	
5a using leisure time the way one wants			.79	
6g seeing people as often as one wants			.79	
10 living life the way one wants			.81	
6a talking to people close to one on equal terms				.82
6b relationships with people who are close to one				.66
6c the respect from people who are close to one				.66
6d one's relationships with acquaintances				.69
6e the respect one receives from acquaintances				.64
6f having an intimate relationship				.51
7a helping or supporting people in any way				.66

*crossloadings

Table 4. Tests of measurement invariance of the IPAFin in men and women with MS with three different models and the comparisons of the models

Model	χ^2	df	χ^2_{diff}	Δdf	p-value	CFI	TLI	RMSEA	SRMR
M1	912.44	558	-	-	-	0.90	0.88	0.08	0.07
M2	922.40	580	16.17	22	0.807	0.90	0.89	0.08	0.08
M3	951.36	601	28.79	21	0.119	0.90	0.89	0.08	0.08

M1 = Freely estimated factor loadings

M2 = Equal factor loadings

M3 = Equal indicator intercepts

χ^2 = Chi-squared statistic, df = Degrees of freedom, χ^2diff = Chi-squared difference test, Δdf = the difference of degrees of freedom, p-value = p-value of chi-squared difference test, CFI = Comparative fit index, TLI = Tucker-Lewis index, RMSEA = Root mean square error of approximation, SRMR = Standardized root mean square residual

Figure 1. The translation process of the IPA for Finnish language

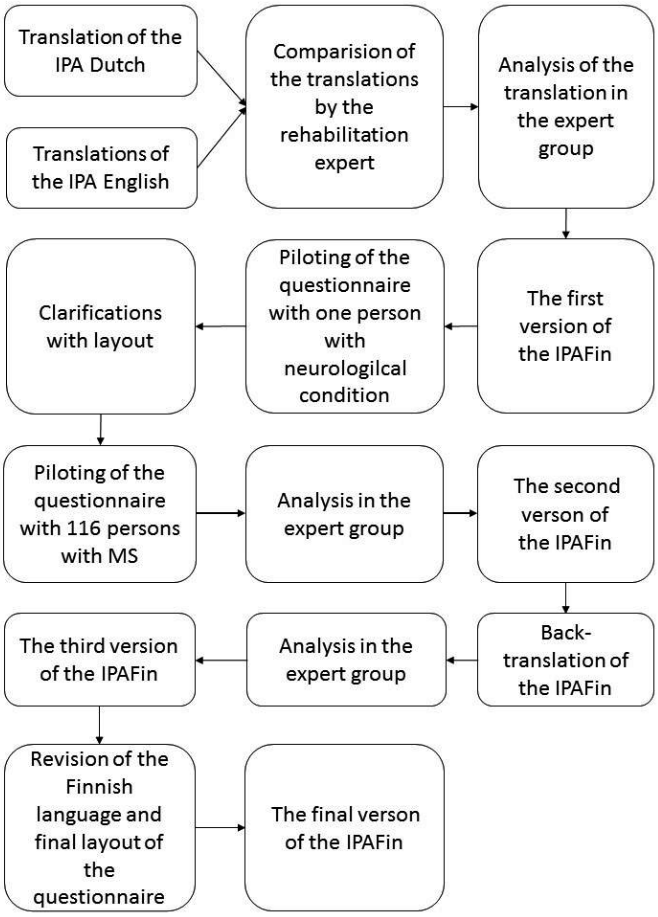
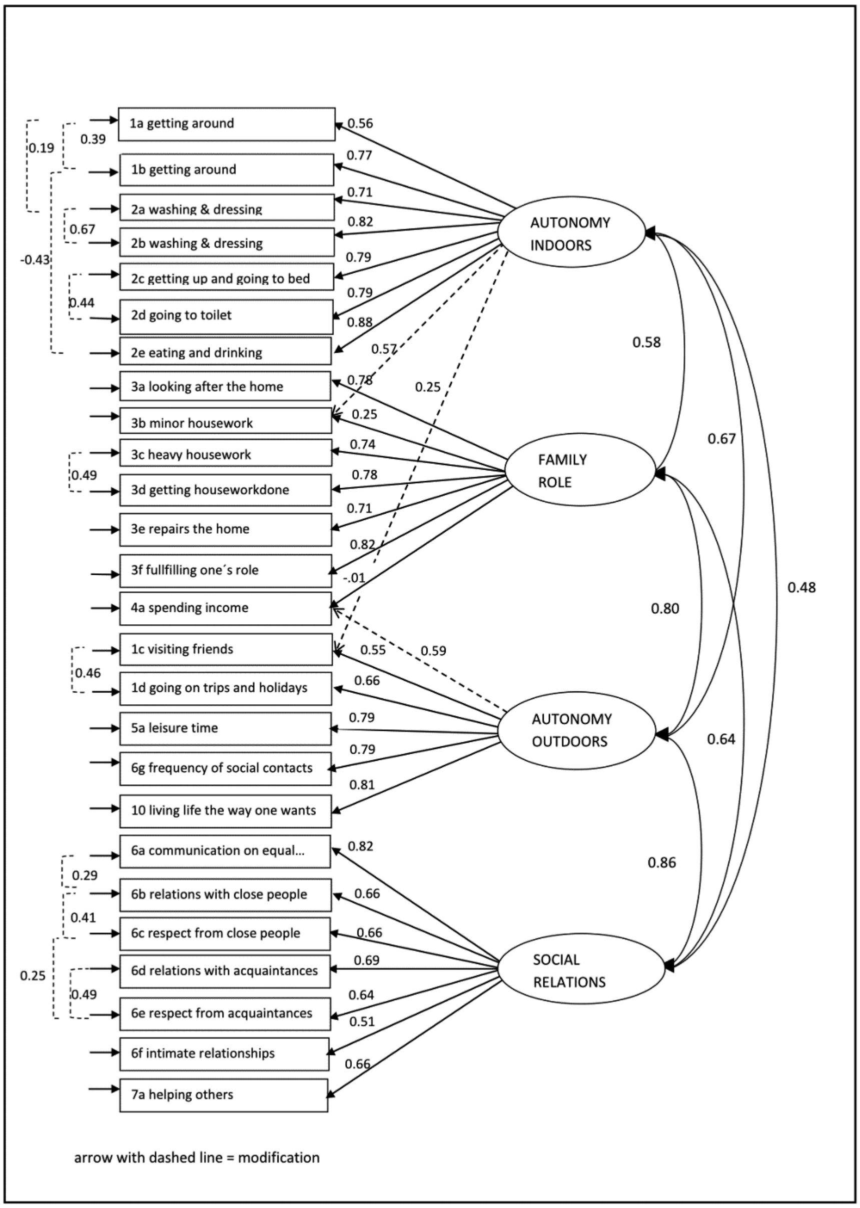


Figure 2. Confirmatory factor model for the modified IPAFin four factor solution.



II

THE ACTIVITIES AND PARTICIPATION CATEGORIES OF THE ICF CORE SETS FOR MULTIPLE SCLEROSIS FROM THE PATIENT PERSPECTIVE

by

Karhula, M.E., Kanelisto, K.J., Ruutiainen, J., Hämäläinen, P.I. &
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The activities and participation categories of the ICF Core Sets for multiple sclerosis from the patient perspective

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multiple sclerosis , International Classification of Functioning, Disability and Health (ICF), ICF Core Set, client perspective

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Abstract

Purpose: To validate the activities and participation components of The International Classification of Functioning, Disability and Health (ICF).

Methods: In this cross-sectional study, 113 Finnish community-dwelling persons with MS were assessed using a semi-structured interview provided by the Canadian Occupational Performance Measure (COPM) to capture participants' self-perceived problems in everyday activities and participation. Problems were linked to the ICF categories.

Results: Participants identified 527 of the most important occupational performance problems. They covered all chapters of the ICF Activities and Participation components. Forty-one categories out of a total 53 ICF activities and participation categories of the Comprehensive ICF Core Set and four out of five categories of the Brief ICF Core Set were reported on by the participants. The most common category in this sample, 'd920 Recreation and leisure' (145 problems/ 27.5%), is not included in the Brief ICF Core Set.

Conclusions: Most, but not all, ICF activities and participation categories of the ICF Core Sets for MS could be confirmed from the perspective of persons with MS. It is worth considering to add category 'd920 Recreation and leisure' to the Brief ICF Core Set.

Implication for Rehabilitation

- The perceived problems of persons with MS support current versions of the ICF Core Sets for MS.
- The subjective experiences of prioritized problems encountered in everyday life vary considerably among community-dwelling persons with MS.
- Persons with MS often experience problems with recreation and leisure activities.
- Experiences of patient about recreation and leisure activities should be asked more systematically during rehabilitation process and the role of recreation and leisure should be considered when further developing the Brief ICF Core Sets for MS.

Introduction

Multiple Sclerosis (MS) is the most common chronic disabling disease of the central nervous system in young adults. From a lifelong perspective, the course of the disease is unpredictable, most often progressive and polysymptomatic [1]. Common manifestations include fatigue, bladder and bowel disorders, problems with vision, tremors, spasticity, abnormal speech, swallowing disorders, sexual dysfunction, cognitive impairment, mobility problems, pain and depression. All of these, in different combinations, seriously affect the daily activities of persons with MS and their possibilities to actively participate in community [2] .

The International Classification of Functioning, Disability and Health (ICF) [3] connects body, individual and societal perspectives. The ICF contains the following broad components: body functions and structures, activities and participation and environmental factors, as well as personal factors which are not yet coded in the ICF (figure 1). The Activity and Participation component includes nine chapters which consist of 21 domains, 118 second-level categories and approximately 400 third- and fourth-level categories. Altogether, the ICF classification consists of more than 1400 categories.

Insert figure 1 about here

The ICF Core Sets for specific diseases have been developed to serve as tools for applying the ICF in clinical practice [4]. ICF Core Sets are lists of ICF categories selected to capture those aspects of functioning that are most likely affected by a specific disease. ICF Core Sets have been developed through a formal decision-making and consensus process using knowledge from recent studies. The perspective of person with specific disease has been identified via interviews and the expert perspective has been collected via a survey [5].

The Comprehensive and Brief Core Sets for MS were decided upon at the International Consensus Conference [6]. A systematic review identified 269 studies published between 2002 and 2007 concerning areas of functioning, disability and health [6]. Hundred and seventy-three health professionals from 46 countries represented the expert perspective in the Internet-based expert survey [6] and 27 persons with MS represented the perspective of persons with MS on focus groups [7]. Moreover, application of the ICF categories for 205 persons with MS was evaluated via a multicentre empirical study in Germany and Switzerland [8]. The consensus conference included 138 ICF categories in the Comprehensive ICF Core Set for MS. Fifty-three of the categories represented the Activities and Participation component. The Brief Core Set for MS, which includes 18 categories, represents the minimum standard for the description and assessment of functioning in different settings. Five categories of them represent the Activities and Participation component: 'd175 Solving problems', 'd230 Carrying out daily routines', 'd450 Walking', 'd760 Family relationship' and 'd850 Remunerative employment'. Both ICF Core Sets for MS warrant further validation and worldwide applicability studies [6].

During the developmental process of the ICF Core Sets for MS, only one study took into account the perspective of persons with MS [7]. Therefore, it is important to further investigate the validity of the ICF Core Sets from the point of view of the persons with MS using the methods that highlight the priorities of the persons themselves.

The objective of our study was to add evidence to the validation of the activities and participation categories of the ICF Core Sets for MS from the perspective of persons with MS. The specific aim was to explore the problems in everyday activities and participation as perceived by persons with MS.

Material and methods

Design

The study was a multi-centre, cross-sectional study involving participants from the districts of Helsinki, Kuopio, Turku, Jyväskylä and Lahti. The procedure was approved by a Research Ethics Committee of the Finnish Social Insurance Institution. All of the participants gave their written informed consent according to the Declarations of Helsinki 1996 for participation in the study.

Participants

The sample included all participants attending to a two-year multi-professional, group-based out-patient rehabilitation project for persons with MS arranged by the Finnish MS Society together with Finnish Social Insurance Institution, and a comparison group of persons with MS receiving typical care. The inclusion criteria were as follows: (1) aged between 18 and 62 (inclusive) years, (2) a confirmed diagnosis of MS [9] (3), restrictions on functioning in at least two out of the four following domains: cognition, mood, fatigue and body control. Due to the intentions of the multicentre study (see ”design”above) mildly disabled and those who were expected not to benefit from group therapy sessions were excluded if one or more of the following criteria were met: (1) a Mini Mental State Examination (MMSE) score of below 20/30 (severe cognitive decline) [10], (2) a Beck Depression Inventory II score of over 40/63 (severe depression) (BDI-II) [11], (3) an Expanded Disability Status Scale (EDSS) of under 4.0 or over 8.5 [12] and (5) any other medical or mental condition precluding participation.

Methods

The data for the study was collected between July and November of 2010 at the beginning of a two-year, multi-professional, group-based out-patient rehabilitation project for persons with MS. Socio-demographic data, including gender, age and housing and working status, and characteristics about the disease, including the duration of the disease and the disease subtype, were collected. The disability of the participants was evaluated using the EDSS and Barthel Index [13]. The EDSS score ranges in increments of 0.5 from 0 (no impairment) to 10 (death). The lower EDSS grades (0-3.5) are defined by the signs in a neurological examination, while grades 4 and above are largely dependent on ambulation and the use of the upper extremities [12].The Barthel Index is a 21-point scale, where zero represents the greatest dependency and 20 independency with the help of others. Each item describes the discrete activity of a daily living task function, such as bowels, bladder, grooming, toilet use, feeding, transfer, mobility, dressing, walking up and down stairs, and bathing [13]. Depression was measured using the BDI-II. It is a 21-item self-assessment inventory of the symptoms of depression in which a higher score represents more problems with mood. A total score of between 14 and 19 is considered to be a sign of mild depression, between 20 and 28 to be a sign of moderate depression, and between 29 and 63 to be a sign of severe depression [11].

The Canadian Occupational Performance Measure (COPM) was used to capture participants' self-perceived problems in everyday activities and participation. Four occupational therapists who were trained to use the COPM in a similar way interviewed the participants during home visits. The COPM is a semi-structured interview designed to identify activities that the participant wants, needs or is expected to perform [14]. In the first phase of the interview, the participant reported those activities that he/ she found difficult to perform. Then each participant rated the importance of each activity using a 10-point scale, with one being not important at all and ten being extremely important. Then, the participant identified up to five activities that she/he considered to be the most important. Finally, the participant rated his/her performance of and satisfaction with these activities. However, this phase of the assessment is not reported in the present report.

Data analysis and linking the data to the ICF activities and participation categories

Problems that the participants prioritized as being most important (1-5 problems per participant) were linked to the corresponding ICF categories based on established rules [15,16] to confirm a systematic and standardized linking process. Before starting the linking process, the researchers (MK & KK) discussed and confirmed the linking and consensus rules. A perceived problem was handled as a unit of analysis which was coded to one ICF category according to the meaning of the perceived problem. For example, if the activity ʻmoving around and enjoying nature' was experienced by participant as a leisure activity in terms of spending time in nature, it was linked to ICF chapter ʹd9 Community, social and civic life', and not to ICF chapter ʹd4 Mobility'. Likewise, during the linking process researchers considered the occasions or context within which the problematic activity occurs and took that into account when linking the activity to ICF category. If needed, the researchers confirmed the meaning of the activity experienced by the participant with the researcher who interviewed the participant. During linking process, researchers documented activities which needed to be considered more closely and the reason for the additional judgment. First, one researcher (MK) linked problems to the ICF second-level categories. Then, another researcher (KK) agreed or disagreed with the choices. After that, the researchers discussed the points of disagreement and reached a consensus. A third researcher (A-LS) was available for consultation in situations in which a consensus could not be reached.

Results:

The characteristics of the participants (n=113) are reported in Table 1. All of the participants had moderate to severe disability and most were economically inactive. The mean of the EDSS score was 6.0 and ranged from 4.0 to 8.5. Majority of the participants were on disability pension (80 %).

Insert table 1. about here.

Linking perceived problems to the ICF activities and participation categories

In the COPM interview, the participants identified 527 of the most important problems that imposed activity limitations and participation restrictions (Table 2). The number of the most important problems identified per participant varied from one to five. We linked the perceived problems in all of the ICF activity and participation chapters and frequently to the following chapters to following degree: ʹd4 Mobility' (25.4%), ʹd5 Self-care' (15.9%), ʹd6 Domestic life' (18.6%) and ʹd9 Community, social and civic life' (27.7%). Infrequently, problems were linked to the chapters ʻd1 Learning and applying knowledge' (1.7%), ʻd3 Communication' (0.6%) and ʻ d7 Interpersonal interaction and relationships' (2.3%).Further, we linked the perceived problems to 43 second level ICF categories. In total 145 problems (27.5%) were linked to the second-level category ′d920 Recreation and leisure′. The activities in this category varied considerably; they included, for example, enjoying nature, meeting friends, doing crosswords, doing sports/exercising, swimming, going to a concert, movie or theatre and doing handicrafts.

Most of the activities could clearly be linked to ICF categories; for example, the activity ‘cleaning the house′ could be linked to category ′d640 Doing housework′ or the activity ‘putting socks on′ could be linked to category ′d540 Dressing′. Researchers linked twelve out of 527 activities differently from one another and always reached a consensus after discussion. It was not necessary to consult with the third researcher.

Insert table 2. about here

Confirmation of the Comprehensive ICF Core Set for MS: activities and participation

Forty-one out of the 43 second-level categories of participation and activities identified in the present study are included in the Comprehensive ICF Core Set (Table 2). The categories ′d839 Education, other specified and unspecified′ and ′d855 Non-remunerative employment′ are not included in the Comprehensive ICF Core Set. However, less than one percent of problems in activities and participation were linked to those categories.

When using the method based on interviewing the person with MS in some of the categories only a few problems were coded, for example ‘ d240 handling stress and other psychological demands′, ‘d170 basic interpersonal interactions′, ‘d720 complex interpersonal interactions′ although professionals have assessed these problems concerning especially cognition and communication as most frequent. The Comprehensive ICF Core Set includes twelve second- level categories that did not appear in our sample: ′d110 Watching′, ′d160 Focusing attention′, ‘d163 Thinking′, ‘d175 Solving problems′, ‘d177 Making decisions′, ′d220 Undertaking multiple tasks′, ‘d330 Speaking′, ′d360 Using communication devices and techniques′, ′d560 Drinking′, ′d830 Higher education′, ′d870 Economic self-sufficiency′ and ′d930 Religion and spirituality′.

Confirmation of the Brief ICF Core Set for MS: activities and participation

Four out of five second-level categories of the Brief ICF Core Set appeared in our sample: ′d230 Carrying out daily routines′, ′d450 Walking′, ′d760 Family relationship′ and ′d850 Remunerative employment′ . The Brief ICF Core Set also includes the category ′d175 Solving problems′, which did not emerge in our sample.

Discussion

In this study, we validated the ICF categories of the components of Activities and Participation included in the Comprehensive and Brief Core Set for MS using empirical data from a perspective of persons with MS by asking participants about the most important problems related to activity limitations and participation restrictions. We linked the activities to 43 ICF second-level categories.

The results show that the current list of ICF activities and participation categories from the Comprehensive ICF Core Set for MS can be confirmed almost entirely from a perspective of persons with MS by using the COPM semi-structured interview. Twelve categories of the Comprehensive ICF Core Set did not emerge in the perspectives of participants as the most important activity limitations and participation restrictions in this sample. It is, however, possible to find explanations for why some of the categories did not emerge in our sample. Although distinctions between activities and participation have been studied and some principles recommended [17,18,19] , consensus has not been found regarding the distinctions. The focus of the COPM, occupations that client needs to, wants to or is expected to do, and is unable to perform satisfactorily, is more on participation than on activities. The ICF defines participation as involvement in a life situation and activity as the execution of a task or an action by an individual. For example, if the participant reported that he or she had difficulties in focusing their attention, the researcher asked the participant to talk about a particular activity and/or situation affected by the difficulty. Then participant named life situations such as discussing with friends or reading a fairy tale to children.

Participants in the present sample did not report major problems with communication. Instead of activities which could be linked to category ′d830 Higher education′, participants in this sample raised the issue of activities which were linked to the category ′d839 Education, other specified and unspecified′, which consists of activities such as studying foreign language as a hobby. The extent of the disability (as measured by EDSS) was severe for over 60% of participants, and 80% of participants receive a disability pension, which might explain why the participants do not prefer such intensive and long-term education and courses.

The participants in our sample reported four out of five Brief ICF Core Set categories of the component activities and participation (′d230 Carrying out daily routines′, ′d450 Walking′, ′d760 Family relationship′ and ′d850 Remunerative employment′). The category ′d175 solving problems′ did not appear in the present sample. The most common category in the present sample, ′d920 recreation and leisure′, is not included in the Brief ICF Core Set. In previous studies, researchers identified activities linked to the category d920 ‘recreation and leisure’ as highly relevant both from a clinical

perspective [8] and from a perspective of persons with MS [7,20]. The findings of the present study are in line with the findings of previous studies [7,8,20] and support the idea of adding this category to the Brief ICF Core Set for MS.
Our study shows that the subjective experiences of problems encountered in everyday life varied considerably among community-dwelling persons with MS when evaluated using a method that recognizes persons' participation preferences. Hammel et al.[21] also found that persons with disabilities experience participation as a complex and dynamic phenomenon, one which is dependent upon personal choices and environmental influences. Problems participating in everyday activities may vary considerably among persons with MS [22] and may depend on subjective experience [23] . Furthermore, Leonardi et al.[24] have proposed taking the subjective experience of functioning into consideration when defining disability. The results of the present study suggest that the personal variation in the content of possibly perceived problems should be taken into account when using the ICF Core Sets in clinical practice. Moreover, Grill & Stucki [25] remind us that the ICF was not developed as a tool for assessment. Therefore, applying ICF categories directly to clinical practice is questionable.

We used several strategies to verify the trustworthiness of the data analysis. The linking process was performed by two researchers using the guidelines decided upon beforehand. The linking process and the argument for using it were made transparent by using memos. A third researcher was also available to consult with during the linking process. However, there were also limitations in the linking process. Both researchers who linked the problems to the ICF categories were occupational therapists. There is the possibility that other health professionals would have made different decisions. Also, Kappa statistics for agreement [26] could have been used if the judgments would have been made totally independently. However, we chose to use the consensus-making process with rigorous arguments because both researchers were familiar with the data and had discussed it before the linking process.

There are some limitations concerning the context of the study and our ability to make generalizations. First, the characteristics of the present sample are not comparable with a typical sample of persons with MS in all respects. For example, our sample consists of persons with considerable activity limitations (EDSS mean 6), and special inclusion criteria for the study included a restriction on functioning in at least two out of four of the following domains: cognition, mood, fatigue and body control. All of the participants were also motivated to participate in the rehabilitation. Second, the study participants were Finnish residents, which might affect our ability to make generalizations about the results in terms of other cultures and populations. Third, the time of the assessment (late summer) might have had a seasonal effect. However, the participants also mentioned activities which they did not perform during that season, for example snow clearing or walking on the slippery ground.

This study generated new client-oriented evidence on the ICF Core Sets for MS. The perceived problems of persons with MS support current versions of the ICF Core Sets for MS. The role of recreation and leisure should be taken into consideration when further developing the Brief ICF Core Sets for MS.

Further research is needed to validate the ICF categories for the component Activities and participation included in the Core Sets for MS with a more representative sample of persons with MS. The COPM has not been used before to validate the ICF Core Sets. The perspective of persons with disabilities has been studied using interviews with both an open and ICF-based approach [27,28] and focus groups [29] . Our findings indicate that, in addition to the focus group interviews, the COPM uncovers subjective variations in perceived problems regarding activities and participation. Therefore, it is an appropriate method for revealing the perspective of person with disability. In addition to the COPM, it might be appropriate to use methods which address invisible problems such as psychological well-being and cognition. In the future, in order to better validate ICF Core Sets for MS on a cross-cultural basis, it is important to use methods that reveal the perspective of persons with MS.

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Declarations of interest:

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Figure 1. The ICF and the Chapters of Activities and Participation (d1-d9)

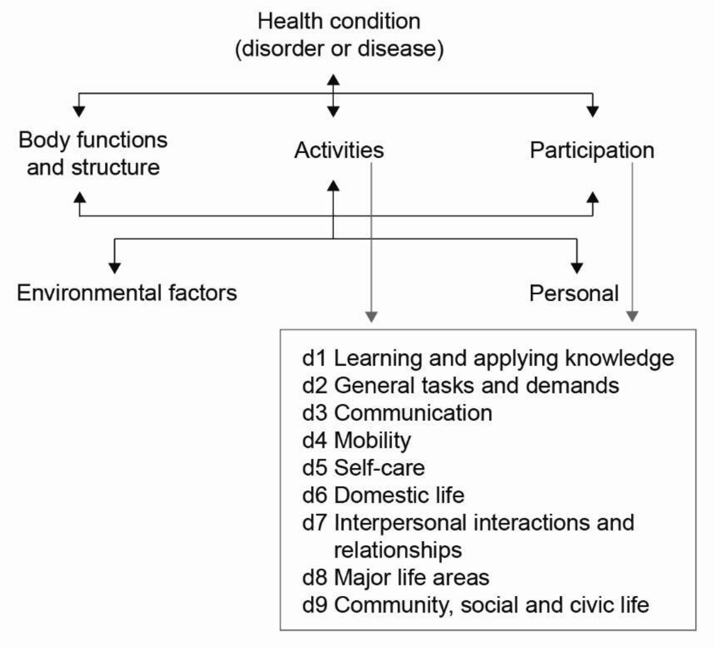

Table1. Characteristics of the Study Participants (n=113)

Mean age yrs (SD/ min–max)	48.4 (8.9 /28–61)
Median duration of disease yrs (min–max)	12 (0–34)
Gender n (%)	
men	34 (30)
women	79 (70)
Living alone n (%)	37 (33)
Employment status n (%)	
disability pension	90 (80)
student	2 (2)
full-time or part-time job	11 (10)
unemployed	3 (3)
sick-leave	7 (6)
Disease severity (EDSS) n (%)	
mean (SD / min–max)	6 (1.3 / 4–8.5)
moderate 4–5.5	43 (38)
severe 6–8.5	70 (62)
Daily functioning (Barthel index)	
median (min–max)	18 (0–20)
Disease subtype n (%)	
relapsing-remitting	45 (39.8)
primary-progressive	28 (24.8)
secondary-progressive	37 (32.7)
unknown	3 (2.7)

Table 2. Number of most important problems (n=527) in the ICF activities and participation categories reported by participants (n=113)

ICF Code	Category title	Number of problems	%
Chapter 1: Learning and applying knowledge		9	1.7
d155	Acquiring skills [1]	2	0.4
d166	Reading [1]	3	0.6
d170	Writing [1]	4	0.8
Chapter 2: General tasks and demands		21	4.0
d210	Undertaking a single task [1]	6	1.1
d230	Carrying out daily routines [1, 2]	14	2.7
d240	Handling stress and other psychological demands [1]	1	0.2
Chapter 3: Communication		3	0.6
d350	Conversation [1]	3	0.6
Chapter 4: Mobility		134	25.4
d410	Changing basic body position [1]	7	1.3
d415	Maintaining a body position [1]	5	0.9
d420	Transferring oneself [1]	5	0.9
d430	Lifting and carrying objects [1]	19	3.6
d440	Fine hand use [1]	2	0.4
d445	Hand and arm use [1]	7	1.3
d450	**Walking** [1,2]	**23**	**4.4**
d455	Moving around [1]	13	2.5
d460	**Moving around in different locations** [1]	**36**	**6.9**
d465	Moving around using equipments [1]	5	1.0
d470	Using transports [1]	6	1.1
d475	Driving [1]	6	1.1
Chapter 5: Self-care		84	15.9
d510	**Washing oneself** [1]	**28**	**5.3**
d520	Caring for body parts [1]	19	3.6
d530	Toileting [1]	7	1.3
d540	**Dressing** [1]	**23**	**4.4**
d550	Eating [1]	5	0.9
d570	Looking after one's health [1]	2	0.4
Chapter 6: Domestic life		98	18.6
d620	**Acquisition of goods and services**[1]	**22**	**4.2**
d630	**Preparing meals**[1]	**22**	**4.2**
d640	**Doing housework**[1]	**29**	**5.5**
d650	**Caring for household objects**[1]	**24**	**4.6**
d660	Assisting others[1]	1	0.2
Chapter 7: Interpersonal interactions and relationships		12	2.3
d710	Basic interpersonal interactions[1]	1	0.2
d720	Complex interpersonal interactions[1]	1	0.2
d750	Informal social relationships[1]	4	0.8

d760	Family relationship[1,2]	3	0.6
d770	Intimate relationship[1]	3	0.6
Chapter 8: Major life areas		20	3.8
d825	Vocational training[1]	1	0.2
d839	Education, other specified and unspecified	3	0.6
d845	Acquiring, keeping and terminating a job[1]	1	0.2
d850	Remunerative employment[1,2]	9	1.7
d855	Non-remunerative employment	2	0.4
d860	Basic economic self-sufficiency[1]	4	0.8
Chapter 9: Community, social and civic life		146	27.7
d910	Community Life[1]	1	0.2
d920	**Recreation and leisure**[1]	**145**	**27.5**
Total	Most important problems	527	100.0

[1] included in the Comprehensive ICF Core Set

[2] included in the Brief ICF Core Set

n≥20 as bold

III

PREDICTORS OF PARTICIPATION AND AUTONOMY IN PEOPLE WITH MULTIPLE SCLEROSIS

by

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IV

SELF-REPORTED REASONS FOR CHANGES IN PERFORMANCE OF EVERYDAY LIVING DURING TWO-YEAR MULTIDISCIPLINARY MS REHABILITATION

by

Karhula, M., Kanelisto, K., Hämäläinen, P., Ruutiainen, J., Häkkinen, A., Era, P.
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