



Háskólinn
á Akureyri
University
of Akureyri

Work Participation of People with MS

Elena Maltseva

HEILBRIGÐISVÍSINDASVIÐ

Lokaverkefni til BS gráðu í iðjuþjálfunarfræði

Iðjuþjálfunarfræðideild

Mái 2018

Verkefni þetta er lokaverkefni til BS gráðu í iðjuþjálfunarfræði

Verkefnið vann:

Elena Maltseva

Leiðbeinandi:

Guðrún Pálmadóttir

Abstract

Multiple Sclerosis (MS) is the most commonly diagnosed chronic and progressive neurological condition affecting working age young adults. As many as 70-80% of people diagnosed with MS become unemployed within 5 years after the diagnosis. The objective of this paper was to get an organized overview of health-related and contextual factors associated with work participation of people with MS, support in employment available to them, and their main concerns regarding support in employment. A systematic review was carried out using peer-reviewed articles in the following databases: OTseeker, PubMed, Cochrane library, CINAHL, and EBSCO. Twenty-two studies were selected for reviewing. The results indicate that changes in employment of people with MS can be explained by both health-related and contextual factors. However, considerably more data is available on the impact of health-related factors on work participation than that of contextual factors. There is also a lack of data on the interaction between health-related and contextual factors in relation to employment of people with MS. The findings also suggest that few people with MS seek or receive any form of employment support despite the fact that it generally has a positive effect. However, people with MS know what kind of support they need and how it should be delivered. They want timely interventions and emphasize a need for provision of information about available services, legal rights, and necessary accommodations. They also want support in disclosure and education of others about MS. These findings have possible implications for healthcare professionals and social policy makers who need to understand the complex interaction between health-related and contextual factors in determining the employment status of people with MS.

Key concepts: health-related factors, contextual factors, employment, work participation, employment support, and vocational rehabilitation.

Útdráttur

Atvinnuþátttaka fólks með MS

MS er langvinnur og versnandi taugasjúkdómur og sá algengasti hjá ungu fólki á vinnualdri. Allt að 70-80% þeirra sem greinast með MS hætta að vinna innan fimm ára frá greiningu. Tilgangur þessa verkefnis var að fá kerfisbundið yfirlit yfir heilsustengda og aðstæðubundna þætti sem tengjast atvinnuþátttöku fólks með MS. Einnig að fá yfirlit yfir þann atvinnustuðning sem stendur fólki með MS til boða auk ábendinga þess m.t.t. atvinnustuðnings. Kerfisbundin leit í OTseeker, PubMed, Cochrane library, CINAHL og EBSCO gagnasöfnum skilaði 22 greinum sem teknar voru til rýningar. Niðurstöðurnar sýndu að atvinnuþátttaka fólks með MS skýrist af bæði heilsutengdum þáttum og þáttum í umhverfinu. Gögn um áhrif heilsutengdra þátta á atvinnu eru töluvert umfangsmeiri en þau sem lúta að umhverfinu. Þá er einnig skortur á gögnum um samspil heilsu og aðstæðna fólks með MS. Niðurstöðurnar gáfu auk þess til kynna að fáir einstaklingar með MS leita eftir eða fá atvinnustuðning þrátt fyrir jákvæð áhrif slíks stuðnings. Fólk með MS er samt meðvitað um hvers konar stuðning það þarf og hvernig honum ætti að vera háttáð. Þau kjósa íhlutun snemma í sjúkdómsferlinu með áherslu á upplýsingagjöf um þjónustu, réttindi og nauðsynlegar breytingar á umhverfi. Einnig kjósa þau að fá aðstoð við að upplýsa vinnuveitendur og vinnufélaga um greininguna og um sjúkdóminn til að koma í veg fyrir mismunun. Niðurstöðurnar hafa hagnýtt gildi fyrir fagfólk í heilbrigðisþjónustu og stefnumótunaraðila sem þurfa að hafa góða innsýn í híf flókna samspil heilsu og umhverfis þegar kemur að atvinnuþátttöku fólks með MS.

Lykilhugtök: heilsutengdir þættir, umhverfisþættir, atvinnuþátttaka, atvinnustuðningur og starfsendurhæfing.

Acknowledgements

I would like to begin by expressing deep gratitude to my instructor, Guðrún Pálmadóttir, for her guidance and encouragement. Her experience, knowledge, and insights were greatly appreciated.

I am also very thankful to my family for their patience and understanding. Special thanks to my husband for all the support and help he offered me through the years of studying and to my mother-in-law for watching our daughter when I needed to study or write in peace. I simply could not have done it without them.

Last but not least, I am grateful to all the teachers at the Department of Occupational Therapy for their dedication to the profession and for being an inspiration to me.

TABLE OF CONTENTS

CHAPTER I: INTRODUCTION.....	1
The MS Disease.....	1
Employment of people with MS.....	3
Rationale and Purpose.....	4
Theoretical Perspective and Definitions of Key Concepts.....	5
Materials and Methods.....	7
CHAPTER II: RESULTS.....	8
Health-related Factors and Work Participation.....	8
Level of neurological impairment.....	8
Physical problems.....	9
Cognitive and psychological problems.....	11
Disease duration and MS type.....	12
Personal Factors and Work Participation.....	13
Age and gender.....	13
Education and professional status.....	13
Income and marital status.....	14
Ethnicity and personality style.....	14
Environmental Factors and Work Participation.....	14
Physical environment.....	15
Social and attitudinal environment.....	16
Institutional environment.....	17
Support in Employment Available to People with MS.....	18

Job accommodations.....	19
Information provision.....	20
Counselling and guidance.....	20
Job search, job placement assistance, and on-the-job support.....	21
Vocational training and college education.....	21
Financial assistance.....	21
Concerns of People with MS Regarding Support in Employment.....	22
Support in managing performance at work.....	22
Support in disclosure.....	22
Service delivery and promotion.....	23
CHAPTER III: DISCUSSION.....	24
Summary of Results.....	24
Interaction between a Health Condition and Contextual Factors.....	25
Implications for Practice.....	26
Implications for Future Research.....	28
CHAPTER IV: CONCLUSION.....	29
REFERENCES.....	30
APPENDIX.....	35
Table 1: Reviewed studies.....	35

Chapter I

Introduction

Work participation plays an important part in people's life. Employment provides people with financial security and therefore opportunities for maintaining or improving their standard of living. It provides structure to the day, social interactions as well as opportunities to form and develop relationships. Through work as a meaningful occupation people can gain a higher self-esteem, a sense of usefulness, satisfaction, and purpose in life (Johnson et al., 2004; Uccelli, Specchia, Battaglia, and Miller, 2009; Doogan and Playford, 2014). Various factors can limit people's ability to participate in employment among which are impairments caused by chronic diseases. Multiple Sclerosis (MS) is the most commonly diagnosed chronic and progressive neurological condition affecting working age young adults and contributing to various levels of disability. An estimated two and a half million people in the world live with MS. People are typically diagnosed between the ages of 15 and 50 years, with the peak age of onset being 20-30 years (Forwell, Hugos, Copperman, and Ghahari, 2014). With the exceptions of some ethnic groups, MS is more prevalent in areas farthest from the equator. Women are two to three times more likely to develop MS than men, with Caucasians from northern Europe being at greatest risk (National Multiple Sclerosis Society, n.d.). On average 25 people get diagnosed with MS every year in Iceland (Ólöf Jóna Elíasdóttir, Elías Ólafsson, and Ólafur Kjartansson, 2009)

The MS Disease

MS is one of the most intrusive diseases affecting all aspects of people's life (Shahrbanian, Duquette, Ahmed, and Mayo, 2016). As many as 80% of people with MS experience restrictions in daily activities (Wynia, Middel, van Dijk, de Keyser, and Reijneveld, 2008). Symptoms and difficulties commonly associated with MS include fatigue,

weakness, cognitive and sensory changes, pain, spasticity, impaired balance and coordination, walking difficulties, visual disturbances, bowel and bladder issues, dysphagia, dizziness or vertigo, tremor, sexual dysfunction, speech problems, heat sensitivity, and depression (Forwell et al., 2014). Though all these can cause discomfort, some have a greater impact on participation in everyday activities than others. Fatigue, for example, affects 60-80% of people with MS and contributes significantly to the overall disability and the increase of other symptoms. Cognitive problems are experienced by up to 65% of people with MS. There can be a considerable variation in the severity of cognitive impairments, but they are still likely to have a negative effect on participation in everyday occupations. Pain is experienced by 40-60% of people with MS, with 48% of them reporting chronic pain. Pain has a significant impact on people's quality of life and independence. Spasticity tends to affect lower extremities and can lead to significant activity limitations (Forwell et al., 2014; National Multiple Sclerosis Society, n.d.).

Multiple Sclerosis (MS) is caused by the breakdown of myelin, damage to axons, and changes in the white and grey matter of the central nervous system (CNS) (Murray, 2006). The exact cause of MS is still unknown, but it is believed that both environmental triggers and genetic factors play a part in it. The word "multiple" refers to both time and location of MS lesions and relapses. The word "sclerosis" refers to the scar tissue that is left by autoimmune attacks on the CNS (Forwell et al., 2014). Four types of MS have been identified: Clinically Isolated Syndrome (CIS), Relapsing-remitting MS (RRMS), Primary progressive MS (PPMS), and Secondary progressive MS (SPMS). CIS refers to the first episode of neurologic symptoms caused by inflammation and demyelination in the CNS. Not all people who experience CIS go on to develop MS. RRMS is the most common type of MS, and about 85% have this form. It is characterized by clearly defined episodes in which new or increased neurologic symptoms appear. These episodes are referred to as relapses. Relapses

are followed by periods of partial or complete remission during which all symptoms may disappear. However, some symptoms may continue and become permanent. PPMS is characterized by a steadily increasing disability from the onset of symptoms and by the absence of early relapses and remissions. About 15% of MS patients have this form. SPMS usually starts as RRMS, and most people diagnosed with RRMS tend to eventually develop SPMS in which neurologic function progressively worsens over time (National Multiple Sclerosis Society, n.d.; Murray, 2006).

Employment of People with MS

A vast majority of people get diagnosed with MS in early adulthood, at the time when it is common to start developing careers. Therefore, it is important to consider the impact of the MS diagnosis on their employment and quality of life (Uccelli, Specchia, Battaglia, and Miller, 2009). Even though work may be stressful at times, its loss can have far reaching emotional, social, and financial consequences for people with MS. With the loss of a job people lose a major role in life. A lack of roles can have a negative impact on their identity, self-esteem, purpose, and structure in everyday life (Kielhofner, 2008). Premature retirement also means a loss of substantial income. MS is considered a costly disease for society as well as for individuals and their families. Based on the data from 15 countries, the average total cost of MS per person a year is 41,335 US dollars with the loss of productivity/work constituting 13% to 74% of that amount (Trisolini, Honeycutt, Wiener, and Lesesne, 2010). About 80% of people with MS who lose their jobs within a decade of being diagnosed do not have sufficient retirement savings. At the same time, they deal with considerable medical costs which tend to increase with the progression of the disease (Kornblith, 1986 in Khan, Ng, and Turner-Stokes, 2009). Considering the early onset of the disease and the fact that people with MS have a near-normal life expectancy, exiting employment at the prime of their

working years means that they and their families have to deal with consequences of unemployment for a long time (Townsend, 2008). Furthermore, unemployed people with MS experience difficulties with returning to work and are at risk of being socially isolated (Kornblith, 1986 in Khan et al, 2009). They report significantly lower quality of life and mood, and higher levels of depression than their employed peers (Dorstyn, Roberts, Murphy, and Haub, 2017). Because of the association between work participation and health-related quality of life in people with MS, it has been suggested that employment should be considered an important health intervention for them (Chiu et al., 2015).

At diagnosis most people are working or studying full-time, and 90% of them have a work history (Bishop et al., 2013). However, due to the unpredictable nature of this condition and a wide range of symptoms associated with it, as many as 70-80% of people diagnosed with MS become unemployed within 5 years after the diagnosis (Johnson et al., 2004). Many of them stop working before the physical limitations become significant (Sweetland, Howse, and Playford, 2012). For years, researchers have tried to find an explanation as to why people with MS choose to leave employment prematurely while, at the same time, the majority of them say that they want to work and believe work to be important for their well-being (Sweetland, Riazi, Cano, and Playford, 2007).

Rationale and Purpose

Considering the overall value of work, frequency of MS among working-age population, early retirement, and high rates of unemployment among people with MS, there is a need for more research on factors that are related to work participation of this group (Moore et.al, 2013; Bishop et al., 2015). Furthermore, vocational rehabilitation of people with MS has received relatively little attention in research (Rumrill, Fraser, and Johnson, 2013; Doogan and Playford, 2014). Understanding barriers to and facilitators of employment of

people with MS can help health professionals and welfare service providers to develop interventions to support and, hopefully, increase their work participation.

The purpose of this paper is to get an overview of factors that are related to work participation of people with MS, support in employment that is available to them, and the main concerns that they have regarding support in employment. This paper will be guided by the following research questions:

1. What health-related factors are associated with work-participation of people with MS?
2. What contextual factors are associated with work-participation of people with MS?
3. What support in employment is available to people with MS?
4. What are the main concerns of people with MS regarding support in employment?

Theoretical Perspective and Definitions of Key Concepts

This paper will be guided by the International Classification of Functioning, Disability and Health (ICF) model. This theoretical perspective has been chosen because it provides a common international language of communication for various professionals who work with this group of clients.

The key concepts in this paper are health-related factors, contextual factors, personal factors, environmental factors, physical environment, social environment, attitudinal environment, institutional environment, employment/work participation, and employment support/vocational rehabilitation. Following are the definitions of these concepts.

Health-related factors refer to impairments or deviations in physical and psychological functions (World Health Organization, 2002) as well as disease duration and level of neurological impairment.

Contextual factors refer to personal and environmental factors (World Health Organization, 2002).

Personal factors include e.g. gender, age, social background, education, profession, and personality characteristics (World Health Organization, 2002).

Environmental factors include aspects of physical, social, attitudinal, and institutional environment (World Health Organization, 2002).

Physical environment encompasses design and construction of buildings people use privately and publicly as well as products for use in daily lives, communication, and transportation. It also includes natural environment (light, temperature and sounds) and human-made changes to the environment (World Health Organization, 2003).

Social environment refers to relationships and support from immediate or extended family, friends, colleagues, health professionals, and people in authority (World Health Organization, 2003).

Attitudinal environment includes individual attitudes of family members, friends, colleagues, and health professionals; societal attitudes; and social norms or practices (World Health Organization, 2003).

Institutional environment refers to a category of environmental factors in ICF that include services, systems, and policies (World Health Organization, 2003).

Employment and work participation refer to engaging in work for payment. Included is self-employment, part-time and full-time employment (World Health Organization, 2003).

Support in employment refers to vocational rehabilitation and other strategies used to help people with MS remain in their current work, modify their work, find new work, or give up work in a planned manner with considering finances and leisure opportunities (Sweetland, Riazi, Cano, and Playford, 2007).

Materials and methods

To answer the research questions a systematic review of peer-reviewed articles was performed in the following databases: OTseeker, PubMed, Cochrane library, CINAHL, and EBSCO. These electronic databases were searched using key words “multiple sclerosis”, “employment”, “work”, “work participation”, and “vocational rehabilitation”. The search period covered the years from 2005 to 2017. The English language restriction was applied. The headings of the articles were reviewed followed by the skimming of the abstracts of all potentially relevant studies. Articles that appeared to address one or more of the above-mentioned research questions and available in full text were selected for reading. Pertinent studies cited in the text of these articles were also obtained. Qualitative, quantitative, and meta-analytical studies were included, but studies focusing on only one type of MS were excluded. Studies that provided evidence pertaining to at least one of the research questions were selected for reviewing.

The paper includes four chapters. The next chapter presents the results followed by discussion in chapter three and conclusion in chapter four.

Chapter II

Results

The search led to the selection of 22 studies. Fourteen of them were quantitative, three were qualitative, three employed mixed methods, and two were meta-analytical studies. The description of the studies can be found in Table 1 (see Appendix). Data came from the United States, Australia, and Europe. The results are organized and presented under five main themes that are connected to the research questions. The first three themes describe health-related, personal, and environmental factors that are associated with work participation of people with MS. The fourth theme concerns employment support that is available to people with MS, and the fifth is about the main concerns of people with MS regarding support in employment. All the main themes have several sub-themes.

Health-related Factors and Work Participation

Health-related factors include level of neurological impairment; physical, cognitive, and psychological problems as well as disease duration and type of MS.

Level of neurological impairment. In research neurological impairment of people with MS is often measured with the Expanded Disability Status Scale (EDSS). This scale includes an assessment of ambulation and allows researchers to group individuals with MS according to their scores as those with minimal, moderate, or severe impairment. Higher EDSS scores indicate a greater level of neurological impairment (Findling et al., 2015; Strober et al., 2012). Several studies indicate that there is an association between employment of people with MS and the level of their neurological impairment. Findling's et al. (2015) conducted a descriptive (measures and survey) study with 405 participants at a Swiss outpatient MS clinic. Their findings suggested that even minimal levels of neurological

impairment could have a negative influence on the working capability of 24% of people with MS. Several other researchers have found a strong association between level of neurological impairment and employment status (O'Connor, Cano, Torrenta, Thompson, and Playford, 2005; Strober et al., 2012; Smith and Arnett, 2005; Moor et al., 2013; Julian, Vella, Vollmer, Hadjimichael, and Mohr, 2008; Bishop et al., 2013; Bishop et al., 2015).

Physical problems. In Smith and Arnett's (2005) cross-sectional descriptive study (survey and measures) in the United States, 86% of 50 participants identified physical symptoms as the main reason for their work status change. These findings are supported by a large-sample self-report survey that found that ineffective symptom management at work was the primary reason for employment loss of people with MS (Simmons, Tribe, and McDonald, 2010). The most frequently cited physical symptoms associated with changes in employment are fatigue, mobility-related issues, impaired arm and hand function, balance or dizziness, pain, bladder and bowel symptoms, poor vision, and heat sensitivity.

Fatigue. Fatigue has been consistently identified as the main cause of giving up work among people with MS. For example, 69,5% of participants in the previously mentioned study (Simmons et al., 2010) reported fatigue as the reason for leaving workforce. Similar results were obtained by Moore's et al. (2013) survey in the United Kingdom. In their study 30% of 221 participants changed their work hours due to fatigue and 58,8% cited it as the reason for exiting employment. In another large-sample (1260 participants) longitudinal study (4 surveys) in Australia 75,2% of participants reported fatigue to have the most impact on their work (Van Dijk, Kirk-Brown, Taylor, and van der Mei, 2017). Julian et al. (2008) also found fatigue to be predictive of employment status. Their results were based on a cross-sectional (8,867 participants) and longitudinal (8,122 participants) analysis of data from the North American Research Committee on Multiple Sclerosis (NARCOMS) Registry database.

Similar findings were obtained in a mixed-method cross-sectional study in the United Kingdom (O'Connor et al., 2005) and in Findling's et al. (2015) study. Strober's et al. (2012) results of a descriptive (survey and measures) study with 101 participants in the United States were also supportive of these findings. However, Uccelli's et al. (2009) results based on a survey in which they gathered data from 1,141 people in 18 European countries were contradictory.

Mobility limitations. Mobility limitations accounted for early retirement of 72,1% of participants in Moore's et al. (2013) study and 43,8% in Simmons' et al. (2010) study. Several other studies support these findings (Van Dijk et al., 2017; O'Connor et al., 2005; Findling et al., 2015; Uccelli et al., 2009; Bishop et al., 2013; Bishop et al., 2015). The last two studies were large-sample surveys in the United States (with 4,201 and 4,142 participants respectively).

Problems with arms and hands. Problems with arms and hands were identified as the reason for job loss by 39,4% of participants in Simmons' et al. (2010) research. Julian et al. (2008) and O'Connor et al. (2005) also found arm and hand impairments to be predictive of unemployment.

Dizziness and poor balance. Dizziness was reported to impact work by 42,7% of participants in Van Dijk's et al. (2017) study. Poor balance was found to influence employment by Simmons et al. (2010) but not by Uccelli et al. (2009). However, O'Connor et al. (2005) found both of these symptoms to be negatively associated with work participation.

Bowel and bladder symptoms. Bowel and bladder symptoms were cited as the reason for early retirement by 17,6% of participants in Moore's et al. (2013) study. Their findings are supported by Simmons et al. (2010) where 28,3% of people reported leaving employment due to these problems. However, no such association was found by Uccelli et al. (2009).

Pain. Pain was found to be associated with work loss by Shahrbanian, Auais, Duquette, Anderson, and Mayo's (2013) meta-analysis of ten articles. Their findings are supported by the studies performed by Findling et al. (2015) and Simmons et al. (2010).

Impaired vision. Several studies have shown impaired vision to be negatively related to work participation (Uccelli et al., 2009; O'Connor et al., 2005; Simmons et al., 2010). For example, 23,5% of participants in Simmons' et al. (2010) study cited poor vision as the reason for leaving employment.

Heat sensitivity. Heat sensitivity was reported to impact work by 51,2% of people in Van Dijk's et al. (2017) study. These findings are supported by the results of Simmons' et al. (2010) study where 34% of participants identified heat sensitivity as a reason for giving up work.

Cognitive and psychological problems. Cognitive problems include issues with attention, memory, executive functions, high level language functions, information processing speed, and visual perceptual skills. Psychological problems refer here to low self-confidence and depression.

Cognitive impairments. Between 35,3% of people in Moore's et al. (2013) and 49,6% in Van Dijk's et al. (2017) study reported exiting workforce due to cognitive impairments. Several other studies have also found cognitive deficits to be predictive of employment loss (Julian et al., 2008; Strober et al., 2012; Uccelli et al., 2009; Bishop et al., 2013; Bishop et al., 2015). Furthermore, cognitive impairments were identified as an area of special concern for people with MS in a focus-group study with 27 participants in the United States (Bogenschuts, Rumrill, Seward, Inge, and Hinterlong, 2016). There difficulties with predicting the impact of cognitive decline on daily functioning and performance at work were found to lead to a loss of self-confidence and uncertainty about career.

Low self-confidence. Several studies have indicated that lowered self-confidence was related to changes in employment status. For example, Simmons et al. (2010) found that over 30% of their respondents had left work and 42,7% thought their jobs were at risk because of the feeling that they were not doing a good enough job. Moreover, 20% of 70 respondents (health professionals and disability employment advisers working with people with MS) in Townsend's (2008) survey in the United Kingdom identified loss of self-confidence as the reason for their clients' giving up work. The negative impact of low self-confidence on work participation was also supported by the findings of Bogenschuts' et al. (2016) study.

Depression. According to Townsend (2008), nearly 25% of health professionals considered depression to be the cause of early retirement of their clients with MS. Furthermore, Smith and Arnett (2005) compared people with MS working full-time, working part-time, and not working in relation to demographic and disease variables and symptoms. They found that those working part-time reported the lowest levels of depression among the three groups. Chiu et al. (2015) obtained similar results in their survey in the United States with 157 participants where they examined the relationship between employment status (working full-time, part-time, or being unemployed) and functional disability, health-related quality of life, and life satisfaction of people with MS.

Disease duration and MS type. Moore et al. (2013) found that disease duration was one of the most predictive factors of employment status with longer duration of illness being associated with decreasing levels of employment. Similar findings were obtained by O'Connor et al. (2005), Bishop et al. (2013), Strober et al. (2012), and Findling et al. (2015). However, Smith and Arnett (2005) found no relation between the two.

Some research data point to an association between the type of MS and employment. For instance, the results of the studies by Julian et al. (2008) and Strober et al. (2012)

indicated that a higher proportion of unemployed people had a progressive type of MS. On the other hand, Bishop et al. (2013) did not find MS type to be predictive of employment status.

Personal Factors and Work Participation

Personal factors included here are age, gender, education, professional status, social background (income and marital status), ethnicity, and personality style.

Age and gender. A number of studies have pointed to an association between age and employment of people with MS. For example, Julian et al. (2008) found older age to be predictive of employment loss and younger age to be related to higher likelihood of re-entering employment. Simmons et al. (2010) also found that older people were more likely to leave employment than those who were younger. These findings are supported by Uccelli et al. (2009), Bishops et al. (2013), and Bishops et al. (2015), but neither by Smith and Arnett (2005) nor Strober et al. (2012), who found no relation between age and employment status.

When it comes to the association between gender and work participation of people with MS, data seem to be quite contradictory. Julian et al. (2008), Van Dijk et al. (2017), and Simmons et al. (2010) found that men were more likely to leave work because of MS than women whereas Findling et al. (2015) found that being a female was related to being unemployed. However, Bishops et al. (2013), Strober et al. (2012), and Smith and Arnett (2005) found no association between gender and employment.

Education and professional status. Several studies have found higher levels of education to be related to longer employment (Julian et al., 2008; Findling et al., 2015; Bishops et al., 2013; Bishops et al., 2015; Moore et al., 2013; Uccelli et al., 2009; Smith and

Arnett, 2005). On the other hand, Strober et al. (2012) found no difference in education between employed and unemployed participants in their study. Regarding the association between professional status and work participation of people with MS, Smith and Arnett (2005) found having a more prestigious job with more responsibility to be predictive of longer employment.

Income and marital status. The findings of Bishop et al. (2013) suggested that income and marital status were related to employment with married participants in their study and participants with higher income being more likely to be employed. Financial considerations were also found to be a significant factor by Uccelli et al. (2009). People in their study continued to work because of the income and concerns about their financial future.

Ethnicity and personality style. Ethnicity was reported to be a significant factor by Julian et al. (2008) and Chiu et al. (2013). Their results suggested that Caucasians were more likely to be employed than African Americans or people from other ethnical groups. Furthermore, Strober et al. (2012) argued that personality style could be an important predictor of employment as it affects the way people cope with and manage their illness. Their study showed that employed people with MS were significantly more likely to be persistent. Persistence was defined here as the ability to persevere in doing things that have previously been associated with positive experiences despite fatigue and frustration.

Environmental Factors and Work Participation

Environmental factors refer to the physical, social, attitudinal, and institutional environment in which people live and conduct their lives.

Physical environment. The following aspects of physical environment will be discussed in this section: accessibility at the workplace and at home, transport and location of parking, room temperature and distractions at work.

Accessibility at workplace and home. In O'Connor's et al. (2005) study 39% of participants identified accessibility within the workplace as a factor having a large impact on their employment. Similar results were obtained in Townsend's (2008) research where 44,2% of professionals cited physical barriers in the workplace as a reason for their clients' giving up work. These findings are supported by Simmons et al. (2010) and Bogenschuts et al. (2016). Factors like having an elevator, being conveniently located, and having an easy access to a bathroom were found by Uccelli et al. (2009) to facilitate employment of people with MS. Furthermore, good housing accessibility has been reported to be positively related to work participation (Bishop's et al., 2013).

Transport and location of parking. Almost half of the participants (48%) in O'Connor's et al. (2005) and 20% in Simmons' et al. (2010) study stated that having to use public transportation to get to work was a barrier to employment. According to Townsend (2008), 28,6% of health professionals reported this problem being raised by their clients with MS. Moreover, having to walk long distances from a parking lot was cited as a reason for giving up work by 14,6% of participants in Simmons' et al. (2010) study.

Other aspects of physical environment. In addition to the previously mentioned aspects of the physical environment, such factors as adequate room temperature and limited distractions at work have been found to be significant facilitators of employment for people with MS (Uccelli et al., 2009).

Social and attitudinal environment. According to Townsend (2008), a lack of support and information about available help was the most frequently cited social factor causing people to give up work. O'Connor et al. (2005) found that in general many people with MS feel isolated and are unaware of sources of help. In this section the focus will be on how attitudes of co-workers, family members, and health professionals can impact work participation of people with MS.

Attitudes at work. Many people with MS struggle with disclosing their diagnosis at work. Up to 15,5% of participants in Simmons' et al. (2010) study felt that their work was at risk because of people at work being critical or unhelpful. In addition, 12,6% thought they were not considered for promotions after disclosing their diagnosis. A focus-group study in the United Kingdom by Sweetland et al. (2007) showed that all 24 participants saw disclosure as a risk due to fears of stigma and possible discrimination. Furthermore, a questioning of competency by colleagues and employers after diagnosis disclosure was an issue discussed by the respondents in Bogenschuts' et al. (2016) study. Most of the time this questioning was experienced as subtle, but at times it was done openly, and some people were fired from their jobs because their supervisors were not convinced of their capability to do the job well. For those participants in the study who wanted to regain employment, knowing that their competency was being constantly questioned was a barrier to returning to work. Furthermore, Kirk-Brown and Van Dijk's (2014) conducted a study in Australia with 40 participants using both focus-groups and individual interviews to explore experiences of people with MS in relation to disclosure. They found that when managers' response to the diagnosis disclosure focused on the disability, they were more likely to discriminate them by overlooking them for promotions, scrutinizing everything they did, assigning to them menial work tasks, or withholding acknowledgement and appreciation of their previous contributions. In this kind of attitudinal environment, the participants were likely to feel a lack of respect and trust

toward them which led to a loss of self-confidence and often a decision to retire. On the other hand, when the supervisors' response focused on the employees' abilities, they were more likely to trust the employees' self-assessment of capability to undertake various tasks, encourage their input into decisions about necessary adaptations, and in some cases even create new jobs for them. In such a climate of trust and appreciation the participants felt valued, their self-confidence was strengthened, and they were less likely to leave employment.

Frndak et al. (2016) conducted a mixed-method research in the United States gathering data cross-sectionally from 143 participants with MS, longitudinally from 103, and through a case study of 6 people. They examined the effects of disclosure on employment and found that although disclosure could contribute to problems at work (e.g. discrimination), it could also lead to necessary accommodations, and thus allow people with MS to remain longer in employment.

Attitudes of family members and health professionals. Attitudes and support from family members and health professionals have also been found to impact employment of people with MS. For instance, Townsend's (2008) findings indicate that some people give up work because of pressure from their families and a lack of encouragement from healthcare professionals. In fact, doctors' or other health professionals' advice to stop working was cited as a reason for retirement by 28,5% of people in Simmons' et al. (2010) study.

Institutional environment. Such aspects of employment as flexible work conditions and social policy on disability benefits have been found to have a significant impact on employment of people with MS.

Flexible work conditions. Simmons et al. (2010) found that 22,3% of participants in their study retired early because company rules or regulations did not allow flexible work

hours or other conditions. On the other hand, being allowed to take regular rest times and time off when needed, receiving assistance with work, and having a flexible work schedule have been identified as factors facilitating employment (Uccelli et al., 2009).

Social policy on disability benefits. The negative association between rights to disability benefits and work participation was reported by Chiu et al. (2013) who analysed data from the Rehabilitation Services Administration for 1920 people with MS in the United States. Moreover, Bishop et al. (2015) found that disability benefits were the most important predictor of employment status among the participants in their study. They argued that a right to disability benefits could be a strong systemic obstacle to employment for people with MS because once they get approved for disability benefits, they are unlikely to return to work if it means that they could lose the benefits. The reason for this was explained by the participants of Bogenschuts' et al. study (2016). Many of them saw disability benefits as vital because of the unpredictable nature of MS. Losing this source of income was a risk they were not willing to take. In some cases, people had to reduce their work hours in order to keep the benefits even though they were capable of working more. Other participants, with previously well-paid jobs, considered keeping disability benefits so important that they were willing to have a lot less money and undergo major lifestyle changes in order to protect them.

Support in Employment Available to People with MS

Support in employment refers to vocational rehabilitation (VR) and other strategies used to help people with MS remain in their current work, modify their work, find new work, or give up work in a planned manner with considering finances and leisure opportunities (Sweetland et al., 2007). This support can come from health and employment professionals working in vocational rehabilitation or other settings. Support in the form of on-the-job accommodations can be provided by employers. A range of services offered by VR agencies

may vary from country to country. Only the most frequently provided VR services for people with MS will be reported here. They include job accommodations; information provision; counselling and guidance; job search and job placement assistance, and on-the-job support; vocational training and college education; and financial assistance.

Job accommodations. Job accommodations refer to managing performance by accommodating work environment and demands, often through the use of assistive technology (Chiu et al., 2013). The issue of job accommodations came up in several studies. For instance, in the context of VR services, this kind of support was found to be positively associated with employment (Chiu et al., 2013). However, Rumrill et al. (2015) collected data from 1924 people with MS in the United States and found that over 50% of the participants did not know how to discuss job accommodation needs and options with their employers. Yet, Van Dijk's et al. (2017) survey in Australia with 1260 participants revealed that not asking for accommodations from employers was one of the biggest regrets of people with MS who gave up work early. Only 40% of participants in their study requested changes to their work role (e.g. different tasks and responsibilities or a flexible work schedule) and 22% to the work environment (e.g. toilet access, assistive technology, air conditioning). However, of those who required changes to their work role, 95% reported receiving them while 82% of those who asked for changes to the work environment reported those changes being made. Frndak et al. (2015) found that the most frequently provided accommodations were flexible work hours, use of fan at work-station or air conditioner, access to refrigerator for cooling products, and convenient parking. Furthermore, Rumrill, Fraser, and Johnson (2013) gathered data through structured telephone interviews with 41 people in the United States and found that equipment and assistive technology (e.g. computer-related) were the most frequently provided accommodations at work. Schedule modifications were also provided, though not as

often as requested, and typically included a possibility to work from home. The participants in this study felt that if the accommodation requested was not costly, then it was more likely to be granted. Other reasons for positive response to accommodation requests were employer's desire to keep a good, committed employee and people with MS being able to make the accommodations themselves. The reasons for negative responses to on-the-job accommodations were high costs, the employer's perceived desire to terminate employment after diagnosis disclosure, a lack of trust in employee's capability to perform the job, not wanting to set a precedent for other workers, and not asking for accommodations appropriately. Self-employed participants reported the most autonomy in decisions regarding accommodations.

Information provision. Nearly all of the participants in Townsend's (2008) study reported providing information (e.g. about other services, MS Society, contact details of local disability employment advisers, or legal rights) as an intervention they used to support people with MS in employment.

Counselling and guidance. Counselling and guidance refer to any form of counselling that addresses medical, social, family, or vocational issues with the focus on helping people to achieve a specific employment outcome (Chiu et al., 2013). Health professionals in Townsend's (2008) study reported providing their clients with individual counselling (most frequently on symptom management) and counselling in groups (e.g. on fatigue or lifestyle management where work was discussed as a part of a program). Support in completion of various types of forms and applications was also reported. However, the findings of this study indicated a lack of counselling on cognitive symptoms and on adaptations to the physical environment of the workplace. Counselling and guidance were

reported to be positively associated with employment (Chiu et al., 2013). However, a Cochrane review that examined the effectiveness of VR in the form of counselling with the focus on job retention found evidence in support of this VR service inconclusive (Khan et al., 2011).

Job search, job placement assistance, and on-the-job support. Assistance with job search refers to supporting a client in finding an appropriate job through helping him to prepare a resume, identify appropriate job options, develop interview skills, and sometimes contacting companies on his behalf. Job placement assistance means a referral to a specific job that leads to an interview. On-the-job support includes job coaching, follow-up, and job retention services (Chiu et al., 2013). Job placement assistance and on-the-job support were found to be significant predictors of positive employment outcomes but not assistance with job search (Chiu et al., 2013). Furthermore, a Cochrane review of a study where people with MS were supported via telephone in a job search deemed evidence for the effectiveness of this service inconclusive (Khan et al., 2011).

Vocational training and college education. The former refers to skill and occupation training that prepares people for employment but does not lead to an academic degree or certification. The latter refers to training that leads to a degree or another recognized credential (Chiu et al., 2013). Both of these services were received by more than 10% of people in Chiu's et al. (2013) study but were not found to be positively associated with employment.

Financial assistance. This refers to financial assistance with expenses for food, clothes, and shelter during the period of time people use VR services (Chiu et al., 2013). This

form of support has been shown to significantly increase the chances of becoming employed (Chiu et al., 2013).

Concerns of People with MS regarding Support in Employment

Sweetland et al. (2007) asked 24 employed people with MS about what they wanted from VR services in terms of content and service delivery. Two concerns related to support in employment were identified: a need for support in managing performance at work and a need for support in disclosure. They also indicated when and in what form this support was to be provided and some possible ways of VR service promotion.

Support in managing performance at work. The participants of Sweetland's et al. (2007) study felt that through having a quick and early access to services (e.g. physical or/and occupational therapy) to deal with issues like weakness or fatigue, their performance at work could be improved. Furthermore, changes in performance could be compensated for by accommodations to the work environment, and they wanted help with identifying necessary accommodations. When people felt that they needed to make employment-related changes and consider other work options due to their health condition and job demands, they wanted professional support and information about appropriate alternatives in order to make informed decisions and choices.

Support in disclosure. The participants in Sweetland's et al. (2007) study also wanted help with disclosure of the diagnosis at work and education of employers and colleagues about MS in order to prevent discrimination. As has been mentioned earlier, all participants in this study saw disclosure as a risky step, felt that they had no one to discuss their concerns with, and lived in fear of negative responses from people at work. It caused

some of them to work harder, to the point where they kept on working during relapses in order to prove themselves and not to lose their jobs. They believed that having professional support and being provided with information about their rights could enable them to take time off when necessary, manage their condition better, and ask employers for necessary accommodations. Being provided with accurate information, especially regarding legal rights and job accommodations, was identified as an important concern by the participants in Rumrill's et al. (2015) study as well.

Service delivery and promotion. In relation to service delivery, three important aspects were identified by the participants in Sweetland's et al. (2007) study. The first one was that intervention needed to take place early in the course of illness. Education and support received shortly after the diagnosis could prevent many problems. The second point was the "one on one" form of interaction with professionals which was preferred by all the participants. It was suggested that services could be delivered from the hospital setting with occasional visits to a client's workplace. The third issue concerned having an open access to service providers, i.e. being able to see a specialist without a referral from a doctor every time. The participants also wanted to be able to get a quick response or advice from professionals in times of crisis. Almost all of the participants were unfamiliar with VR services but still they agreed that such services were needed and useful and emphasized the need for raising awareness about VR support. This, they suggested, could be done through leaflets, internet, and posters.

Chapter III

Discussion

The objective of this paper was to get an organized overview of health-related and contextual factors associated with work participation of people with MS, employment support available to them, and the main concerns they have in relation to employment support. Data were gathered through a review of 22 articles.

Summary of Results

The findings indicate that employment of people with MS is influenced by both health-related and contextual factors. Among health-related factors that are negatively associated with work participation are level of neurological impairment; presence of various physical, cognitive, and psychological problems; disease duration; and possibly a progressive type of MS. On the other hand, some personal factors may be predictive of longer employment, the most important being: younger age, higher levels of education, having a more prestigious profession, higher income, being married, and being persistent. Data regarding association between gender and work status are inconclusive. A number of environmental factors that can impact employment of people with MS have been identified. For example, aspects of the physical environment, such as accessibility, type of transport, parking facilities, and working conditions are found to be associated with work participation. A degree of understanding and helpfulness from co-workers, and a level of trust, support, and flexibility from employers are those aspects of social/attitudinal environment of the workplace that can influence employment. In addition, support from family members and healthcare professionals can also affect work-related decisions of people with MS. Moreover, social policies regarding disability benefits have been found to impact their work participation as well.

The results also suggest that few people with MS seek or receive support in employment, whether in the form of VR or any other form, despite the fact that it generally has a positive effect. This is especially true for VR through assistive technology services/job accommodations, counselling and guidance, job placement assistance, on-the-job support, and financial assistance with living expenses while in VR. Most of these services are reflective of the concerns expressed by people with MS. They particularly emphasize a need for provision of information about available services, legal rights, and necessary accommodations and a need for support in disclosure. This employment support, they suggest, should be offered early in the course of illness. It should be individualized (one on one), easy to access, and extend beyond the hospital setting.

Interaction between a Health Condition and Contextual Factors

In ICF functioning is viewed as an outcome of interactions between a health condition and contextual factors (World Health Organization, 2002). Yet, it appears that there is a lot more available data on the impact of the health-related factors than on the influence of the contextual factors on employment. This unevenness in research attention might be reflected in the knowledge and skills of healthcare professionals as well as in their interventions. According to Townsend (2008), their interventions tend to be focused more on symptoms than on physical and social barriers of the workplace. It is also interesting that there seems to be more data on the effects of physical symptoms on work participation than on the influence of cognitive and psychological problems. The same imbalance is reported in symptom-related interventions. Some data suggest that health professionals address physical symptoms such as fatigue in their interventions a lot more frequently than cognitive issues (Townsend, 2008). However, cognitive problems account for the loss of self-confidence in a lot of people with MS, which in turn causes them to give up work.

There also seems to be a lack of data on the interaction between health-related and contextual factors in relation to work participation of people with MS. However, when considering work participation as an outcome of this interaction, then many of the findings make sense. For instance, being provided with flexible work conditions has been found to be a significant predictor of employment. This association is unsurprising when viewed in the context of the fluctuating nature of this disease and the prevalence of fatigue in people with MS. Moreover, having to manage public transportation, walk long distances from parking lots or within working space, stand a lot, and/or use stairs at work has been identified as a barrier to work participation. This relation makes sense in the light of the fact that many people with MS deal with impaired balance and walking difficulties. Furthermore, low self-confidence has been found to be predictive of work loss. It is no surprise that people with MS with low self-confidence choose to retire when they encounter critical, unhelpful, and unsupportive attitudes from co-workers or a lack of trust and discrimination from employers. Another finding that demonstrates this interaction is that married people of both genders are more likely to be employed longer. A possible explanation for this association is that they might receive more support and assistance with household and child rearing duties from their spouses than their single peers. These findings underscore the importance of understanding the complex nature of MS and the multiple ways in which it can interact with contextual factors to affect work participation of people with MS when trying to support them in employment.

Implications for Practice

The results indicate that it is important to provide people with MS with early interventions aimed at work retention because once people with MS lose work, it seems to be hard for them to regain it. Providing them with information about various available services

right or shortly after the diagnosis should encourage them to look for help when they need it. As a consequence, hopefully more people with MS will seek and receive employment support. However, it is not enough to provide people with MS with information about these services. It is just as important to ensure that they have a quick and easy access to them, and that the services meet their needs. Furthermore, VR should include interventions that address the impact of physical symptoms on work performance as well as interventions that minimize the effect of cognitive deficits and develop self-confidence. Equally important is attention in VR to those aspects of physical and social environment that can influence work-related decisions of people with MS. For instance, support in disclosure and education of co-workers can prevent discrimination and create a healthier working environment. Information regarding legal rights can enable people with MS to take sick leave when needed and to request accommodations from their employers. Various modifications to the work role and to the work environment can compensate for difficulties with job performance and enable people with MS to work longer. Some findings suggest that younger people are more likely to re-enter employment. Therefore, it is important to target them (those under the age of 45) in VR (Julian et al., 2008; Bishop et al., 2015).

Townsend (2008) argues that there should be a change of focus in VR efforts. Instead of trying to help people with MS to return to full-time employment, a greater consideration should be given to part-time work options. However, if people with MS are to choose to cut back on work hours instead of going on a disability pension, then social policies should ensure that they do not lose income by doing so.

On a bigger scale, it is important to consider the needs of disabled people when designing and developing the physical environment of work and living spaces. It is also necessary to continue to make efforts to change the way society views and treats disabled

people, and to make sure that social policies facilitate rather than hinder their participation in work and other activities.

Implications for Future Research

More research is needed into attitudes and concerns of those groups that have been found to affect employment-related decisions of people with MS (i.e. family members, healthcare professionals, and employers). Moreover, since people with MS need support from various specialists who are well familiar with the factors that can influence the outcome of VR, it is important for future research to address their educational needs. Furthermore, as no data in this paper came from Iceland, more research is needed on work participation and employment concerns of people with MS in Iceland.

The limitations of this paper are the absence of data from Iceland and the fact that all data came from the “westernized” countries. Therefore, generalizations from these findings might not be possible to people with MS who live in other cultures with different healthcare and welfare systems.

Chapter IV

Conclusion

MS is a complex disease affecting people at working age. Many people with MS give up work before the physical limitations become significant. Early retirement of people with MS can be explained by both health-related and contextual factors. Considerably more attention in research has been given to the impact of various health-related factors than to the influence of environment. However, several aspects of physical, social, and institutional environment that impact work participation have been identified.

As vocational rehabilitation clients, people with MS have received little attention in research but data suggest that few people with MS seek or receive employment support. However, they know what kind of support they need and how it should be delivered. People with MS want timely interventions that address health-related issues as well as those aspects of physical and social environment that make it difficult for them to remain in employment. In general, it is important to pay more attention to the impact of environment on participation of disabled people in employment and to ensure that physical, social, and institutional environment facilitates it rather than hinders.

More research is needed into concerns of family members of people with MS in relation to employment, into the needs and concerns of employers managing workers with MS, and into the attitudes and educational needs of various professionals working with this group of clients. A lack of data from Iceland points to a need for more research on issues related to employment and vocational rehabilitation of Icelandic people with MS.

References

- Bishop, M., Chan, F., Rumrill, P. D. Jr., Frain, M. P., Tansey, T. N., Chiu, C., ...
 Umeasiegbu, V. I. (2015). Employment among working-age adults with multiple sclerosis: A data-mining approach to identifying employment interventions. *Rehabilitation Research, Policy, and Education, 29*(2), 135-152.
- Bishop, M., Roessler, R. T., Rumrill, P. D., Sheppard-Jones, K., Frain, M., Waletich, B., and Umeasiegbu, V. (2013). The relationship between housing accessibility variables and employment status among adults with Multiple Sclerosis. *Journal of Rehabilitation, 79*(4), 4-14.
- Bogenschutz, M., Rumrill, P.D., Jr., Seward, H.E., Inge, K.J., and Hinterlong, P.C. (2016). Barriers to and facilitators of employment among Americans with Multiple Sclerosis: results of a qualitative focus group study. *Journal of Rehabilitation, 82*(2), 59-69.
- Chiu, C-Y., Chan, F., Bishop, M., da Silva Cardoso, E., and O'Neill, J. (2013). State vocational rehabilitation services and employment in multiple sclerosis. *Multiple Sclerosis Journal, 19*(12), 1655-1664.
- Chiu, C-Y., Chan, F., Sharp, S.E., Dutta, A., Hartman, E., and Bezyak, J. (2015). Employment as a health promotion intervention for persons with multiple sclerosis. *Work Journal, 52*, 749-756.
- Doogan, C. and Playford, D.E. (2014). Supporting work for people with multiple sclerosis. *Multiple Sclerosis Journal, 20*(6), 646-650.
- Dorstyn, D.S., Roberts, R.M., Murphy, G., and Haub, R. (2017). Employment and multiple sclerosis: a meta-analytic review of psychological correlates. *Journal of Health Psychology*. Advanced online publication. [https:// doi: 10.1177/1359105317691587](https://doi.org/10.1177/1359105317691587)

- Findling, O., Baltisberger, M., Jung, S., Kamm, C.P., Mattle, H.P., and Sellner, J. (2015). Variables related to working capability among Swiss patients with multiple sclerosis—A cohort study. *PLoS ONE*, *10*(4): e0121856.
- Forwell, S.J., Hugos, L., Copperman, L.F., and Ghahari, S. (2014). Neurodegenerative diseases. In Rodomsky, M.V. and Trombly, L.C.A. (editors), *Occupational therapy for physical dysfunction* (7. ed.) (pp.1077-1102). Baltimore: Lippincott, Williams and Wilkins.
- Frndak, S.F., Kordovsky, V.M., Cookfair, D., Rodgers, J.D., Winstock-Guttman, B., and Benedict, R.H.B. (2015). Disclosure of disease status among employed multiple sclerosis patients: association with negative work events and accommodations. *Multiple Sclerosis Journal*, *21*(2), 225-234.
- Julian, L.J., Vella, L., Vollmer, T., Hadjimichael, Q., and Mohr, D. (2008). Employment in multiple sclerosis: Exiting and re-entering the work force. *Journal of Neurology*, *255*, 1354-1360.
- Johnson, K.L., Yorkston, K.M., Klasner, E.R., Kuehn, C.M., Johnson, E., and Amtmann, D. (2004). The cost and benefits of employment: a qualitative study of experiences of persons with multiple sclerosis. *Archives of Physical Medicine and Rehabilitation*, *85*, 201-209.
- Khan, F., Ng, L., and Turner-Stokes, L. (2009). Effectiveness of vocational rehabilitation intervention on the return to work and employment of persons with multiple sclerosis. *Cochrane Database of Systematic Reviews*, N.PAG.
- Kielhofner, G. (2008). *Model of human occupation: Theory and application* (4. ed.). Baltimore: Lippincott, Williams and Wilkins.

- Kirk-Brown, A.K. and Van Dijk, P.A. (2014). An empowerment model of workplace support following disclosure for people with MS. *Multiple Sclerosis Journal*, 20(12), 1624-1632.
- Moore, P., Harding, K.E., Clarkson, H., Pickersgill, T.P., Wardle, M., and Robertson, N.P. (2013). Demographic and clinical factors associated with changes in employment in multiple sclerosis. *Multiple Sclerosis Journal*, 19(12), 1647-1654.
- Murray, T. J. (2006). Diagnosis and treatment of multiple sclerosis. *British Medical Journal*, 332(7540), 525–527.
- National Multiple Sclerosis Society. (n.d.). *What is MS? Types of MS*. Retrieved from: <https://www.nationalmssociety.org/What-is-MS/Types-of-MS>.
- National Multiple Sclerosis Society. (n.d.). *Diagnosing MS*. Retrieved from: <https://www.nationalmssociety.org/Symptoms-Diagnosis/Diagnosing-MS>.
- O’Conner, R.J., Cano, S.J., Torrenta, L.R., Thompson, A.J., and Playford, D.E. (2005). Factors influencing work retention for people with multiple sclerosis. *Journal of Neurology*, 252, 892-896.
- Ólöf Jóna Elíasdóttir, Elías Ólafsson and Ólafur Kjartansson. (2009). Multiple Sclerosis - yfirlit um einkenni, greiningu og meðferð. *Læknablaðið*, 95(9), 583-589.
- Rumrill, P. D., Fraser, R. T., and Johnson, K. L. (2013). Employment and workplace accommodation outcomes among participants in a vocational consultation service for people with multiple sclerosis. *Journal of Vocational Rehabilitation*, 39(2), 85-90.
- Rumrill, P.D. and Roessler, R.T. (2015). An overview of Multiple Sclerosis: Medical, psychosocial, and vocational aspects of a chronic and unpredictable neurological disorder. *Rehabilitation Research, Policy, and Education*, 29(2), 122-134.

- Rumrill, P.D., Roessler, R.T., Li, J., Daly, K., and Leslie, M. (2015). The employment concerns of Americans with multiple sclerosis: perspectives from a national sample. *Work Journal*, 52, 735-748.
- Shahrbanian, S., Auais, M., Duquette, P., Anderson, K., and Mayo, N.E. (2013). Does pain in individuals with multiple sclerosis affect employment? A systematic review and meta-analysis. *Journal of Pain Research and Management*, 18(5), 94-100.
- Shahrbanian, S., Duquette, P., Ahmed, S., and Mayo, N.E. (2016). Pain acts through fatigue to affect participation in individuals with multiple sclerosis. *Quality of Life Research*, 25(2), 477-491.
- Simmons, R.D., Tribe, K.L. and McDonald, E.A. (2010). Living with multiple sclerosis: longitudinal changes in employment and the importance of symptom management. *Journal of Neurology*, 257, 926-936.
- Smith, M.M. and Arnett, P.A. (2005). Factors related to employment status changes in individuals with multiple sclerosis. *Multiple Sclerosis Journal*, 11, 602-609.
- Strober, L.B., Christodoulou, C., Benedict, R.H.B., Westervelt, H.J., Melville, P., Scherl, W.F., ... Krupp, L.B. (2012). Unemployment in multiple sclerosis: the contribution of personality and disease. *Multiple Sclerosis Journal*, 18(5), 647-653.
- Sweetland, J., Howse, E., and Playford, E.D. (2012). A systematic review of research undertaken in vocational rehabilitation for people with multiple sclerosis. *Disability and Rehabilitation*, 34(24), 2031–2038.
- Sweetland, J., Riazi, A., Cano, S.J., and Playford, E.D. (2007). Vocational rehabilitation services for people with multiple sclerosis: what patients want from clinicians and employers. *Multiple Sclerosis Journal*, 13(9), 1183-1189.

- Townsend, G. (2008). Supporting people with multiple sclerosis in employment: a United Kingdom survey of current practice and experience. *British Journal of Occupational Therapy*, 71(3), 103-111.
- Trisolini, M., Honeycutt, A., Wiener, J., and Lesesne, S. (2010). Global economic impact of multiple sclerosis. *Multiple Sclerosis International Federation*.
- Uccelli, M., Specchia, C., Battaglia, M.A., and Miller, D.M. (2009). Factors that influence the employment status of people with multiple sclerosis: a multi-national study. *Journal of Neurology*, 256, 1989-1996.
- Van Dijk, P.A., Kirk-Brown, A.K., Taylor, B., and van der Mei, I. (2017). Closing the gap: longitudinal changes in employment for Australians with multiple sclerosis. *Multiple Sclerosis Journal*, 23(10), 1415-1423.
- World Health Organisation. (2002). *Towards a common language for functioning, disability and health ICF*. Geneva: World Health Organisation.
- World Health Organisation. (2003). *ICF checklist*.
<http://www.who.int/classifications/icf/training/icfchecklist.pdf>
- Wynia, K., Middel, B., van Dijk, J.P., de Keyser, J.H., and Reijneveld, S.A. (2008). The impact of disabilities on quality of life of people with multiple sclerosis. *Multiple Sclerosis*, 14(7), 972-980.

Appendix

Table 1.
Reviewed studies

Reference	Study design	Participants
Bishop, Chan, Rumrill, Frain, Tansey, Chiu, . . . Umeasiegbu, 2015	A cross-sectional survey that examined demographic, functional, and clinical MS variables affecting employment status of adults with MS in the United States.	N = 4,142 Age: 20-65 Mean age: 51.93 (SD=8.7) Female: 79,1% Male: 20,9%
Bishop, Roessler, Rumrill, Sheppard-Jones, Frain, Waletich, and Umeasiegbu, 2013	A cross-sectional survey that explored the extent to which housing accessibility variables add to the prediction of employment status of Americans with MS.	N =4,201 Age: 18-65 Mean age: 52.02 (SD=8.7) Female: 79,3% Male: 20,7%
Bogenschutz, Rumrill, Seward, Inge, Hinterlong, 2016	A qualitative study that used phone-administered focus groups to investigate work-related experiences and identify barriers to and facilitators of employment among Americans with MS.	N = 27 (15 unemployed, 12 employed) Age: 18-64 Female in the employed group: 90,9%, male: 9,1% Female in the unemployed group: 64,3%, male: 35,7%
Chiu, Chan, Bishop, da Silva Cardoso, and O'Neill, 2013	A quantitative study in the United States that analysed data retrieved from the Rehabilitation Services Administration database with the objective to identify what vocational rehabilitation services helped MS clients obtain and maintain employment.	N = 1920 Age: 16-64 Mean age: 42.69 (SD=10.99) Female: 68,8% Male: 31,2%
Chiu, Chan, Sharp, Dutta, Hartman, and Bezyak, 2015	A cross-sectional survey that examined the relationship between employment status and functional disability, health-related quality of life, and life satisfaction of people with MS in the USA.	N = 157 Age: 23-55 Mean age: 43.81 (SD=8.15) Female: 86% Male: 14%

Findling, Baltisberger, Jung, Kamm, Mattle, and Sellner, 2015	A cross-sectional descriptive study (measures and survey) that examined variables related to working capability among Swiss patients with MS.	N = 405 Mean age: 44.2 (SD=10.2) Female: 66% Male: 34%
Frndak, Kordovsky, Cookfair, Rodgers, Winstock-Guttmand Benedict, 2015	A mixed-method study in the United States gathering data cross-sectionally (survey and tests), longitudinally (online survey), and through a case study. The objective was to examine the effects of disclosure on employment.	<i>Cross-sectional sample:</i> N = 143 Female/male: 116/27 Mean age: 45.8 (SD = 10.7) <i>Longitudinal sample:</i> N = 103 Female/male: 90/13 Mean age: 45.4 (SD = 9.7) (in both samples: N = 47; case study: N = 6) Age: 18-60
Julian, Vella, Vollmer, Hadjimichael, and Mohr, 2008	Quantitative study that used data from the NARCOMS patient registry. Patient and disease characteristics associated with transitions to unemployment or employment were evaluated cross-sectionally and prospectively over the course of two assessment periods (mean interval of 1.56 ± 0.93 years).	<i>Cross-sectional sample:</i> N= 8,867 <i>Longitudinal sample:</i> N=8,122 Mean age: 47.6 (SD=8.59) Female: 75% Male: 25%
Khan, Ng, and Turner-Stokes, 2009	A Cochrane review of two studies (one RCT and one CCT) in the United States with the objective to determine effectiveness of vocational rehabilitation intervention on the return to work and employment of people with MS.	<i>Study one</i> N = 43 Mean age: 41.6 (SD=9.6) Female: 75,6% Male: 24,4% <i>Study two</i> N = 37 Mean age: 43 Female: 78.4% Male: 21,6%
Kirk-Brown and Van Dijk, 2014	An Australian qualitative study (interviews and focus groups) with the objective to identify the types of psychosocial support that people with MS require post-disclosure in order to maintain their employment status.	N = 40 (individual interviews n=25; focus groups n= 15) Age: 18-65 Mean age: 44.76 Female: 70% Male: 30%

Moore, Harding, Clarkson, Pickersgill, Wardle, and Robertson, 2013	A survey in the United Kingdom which examined demographic and disease-related factors associated with changes in employment.	N = 221 Mean age 45.98 (SD=11.97) Female: 70.4 % Male: 29,6%
O'Connor, Cano, Torrenta, Thompson, and Playford, 2005	A mixed-method cross-sectional study using qualitative methods (interviews) in phase one and quantitative methods (survey and measures) in phase two with the objective to identify factors that impact work retention of people with MS.	<p><i>Phase one</i> N = 62 Age: 19-65 Mean age: 46 Female: 65%</p> <p><i>Phase two</i> N = 100 Age: 20-65 Mean age (employed group) 45 (SD=8) Female: 69% Mean age (unemployed group): 49 (SD=10) Female: 78%</p>
Rumrill, Roessler, Li, Daly, and Leslie, 2015	A survey with the objective to explore employment concerns of Americans with MS.	N = 1,924 Mean age: 53.94 (SD=12.20) Female: 78,7% Male: 21,3%
Rumrill, Fraser, and Johnson, 2013	A descriptive study in the United States that utilized both qualitative and quantitative data elicited through structured phone interviews. The purpose of the study was to identify the outcomes of the accommodation-related assistance that respondents had received and evaluate their current employment status and accommodation experience.	N = 41 Age: 31-62 Mean age: 46.9 (SD=8.4) Female: 63% Male: 37%
Shahrbanian, Auais, Duquette, Anderson, and Mayor, 2013	An extensive systematic review of scientific literature with the objective to determine if pain is associated with employment status of people with MS.	Ten articles

<p>Simmons, Tribe, and McDonald, 2010</p>	<p>A survey with the objective to identify reasons for employment loss among people with MS. Data were gathered through 2 surveys of MS patients performed 4 years apart (2003-2007) in Australia. Employment rates were measured both cross-sectionally and longitudinally.</p>	<p><i>Survey one</i> N = 1,135</p> <p><i>Survey two</i> N = 1,329</p> <p>N (both surveys) = 667</p> <p>The majority of respondents were female.</p> <p>Most of the male and female respondents were in the 45-64 age group.</p>
<p>Smith and Arnett, 2005</p>	<p>A cross-sectional descriptive study (survey and measures) in the United States that tried to identify factors related to employment status changes in people with MS.</p>	<p>N = 50 Mean age: 49.88 (SD=7.59) Female: 76% Male: 24%</p>
<p>Strober, Christodoulou, Benedict, Westervelt, Melville, Scherl, ... Krupp, 2012</p>	<p>A descriptive study (survey and measures) in the United States. The goal of this study was to determine the extent to which personality, demographics, and clinical measures contribute to unemployment in MS.</p>	<p>N = 101 Age: 18-59 Female: 79% Male: 21%</p>
<p>Sweetland, Riazi, Cano, and Playford, 2007</p>	<p>A qualitative study (four focus groups) in the United Kingdom with the aim to identify what people with MS want from a vocational rehabilitation service in terms of content and service delivery.</p>	<p>N = 24 Age: 25-59 Female: 71% Male: 29%</p>
<p>Townsend, 2008</p>	<p>A survey in the United Kingdom that gathered data through a postal questionnaire which included open and closed questions. The aim was to explore the knowledge of work-related issues of people with MS among MS specialists and their experience in supporting people with MS in employment.</p>	<p>N = 70 Occupational therapists: N=32 Nurses: N=26 Physical therapists: N=4 Disability employment advisors: N=8</p> <p>All were experienced professionals working with MS clients for a number of years.</p>

Uccelli, Specchia, Battaglia, and Miller, 2009	A survey that gathered data from 18 European countries and assessed factors that people with MS believed to contribute to their employment status change.	N = 1,141 Age: 21-67 Mean age: 41.8 (SD=9.2) Female: 67% Male: 33%
Van Dijk, Kirk-Brown, Taylor, and van der Mei, 2017	A longitudinal study that gathered data from 2010 to 2013 through four surveys in Australia. The objective was to examine employment status of people with MS compared with the general population, longitudinal changes in employment of people with MS, and the provision of modifications to work role/environment during these years.	N = 1260 A majority of both male and female respondents came from the 45-64 age groups. Most of respondents were female in all age groups.

