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PSYCHOLOGICAL AND SOCIAL ASPECTS OF QUALITY OF LIFE IN MULTIPLE SCLEROSIS WITH A FOCUS ON GENDER AND CULTURE

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TO MY FATHER

I dedicate this thesis to my beloved father, who died many, many years ago.
I hope, the results of this thesis reach persons with MS, their social environment and their medical caregivers. May it help improving the quality of live of those with MS.

Strength does not come from physical capacity. It comes from an indomitable will.

Mahatma Ghandi

Statutory Declaration

I declare that I have authored this thesis independently, that I have not used other than the declared sources/resources, and that I have explicitly marked all material which has been quoted either literally or by content from the used sources.

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Abstract

Multiple sclerosis (MS) is an inflammatory auto-immune disease of the central nervous system. The demyelination of the nerve fibers leads to many impairments both physical and cognitive. The psychological and social effects on the affected, however, have not received sufficient attention in the scientific literature. The goal of this thesis is to analyze the role of psychological and social factors related to the quality of life (QoL) of those with MS. In this thesis, I investigate whether there are differences in gender and nationality. I take a closer look at coping strategies of affected, at the role of personality variables and the aspect of social support. Furthermore I evaluate whether patients perceived positive life changes since being diagnosed MS.
Methods: The gender and intercultural comparison is based on the study being split between Austria and the United States. The sample includes 128 participants, 64 in each country, of whom 50 are men and 78 are women aged between 20 and 57 years. I asked participants in quantitative questionnaires respectively qualitative interviews about psychological and social aspects of their quality of life and their coping strategies for dealing with MS and with stress. In addition to standard statistical tests for the quantitative data I analyzed the qualitative data by identifying categories in response patterns. I controlled possible biases due to the sample selection in the quantitative data analysis and used age, a disability score, MS duration, and educational level as covariates.
Results: Austrian participants perceive a higher social-emotional QoL with MS in comparison to American participants. American participants show a higher self-esteem in comparison to Austrians participants. I identified that men have a lower ability to express love in comparison to women. Independent of gender and nationality, participants reported perceived benefit through the disease, especially with regards to compassion, mindfulness, improved family relations, and personal growth. The qualitative interviews reveal gender and cultural differences in coping strategies and in dealing with the illness and stress. I also found gender and cultural differences in experiences, expectations, and challenges related to MS, especially in the context of health literacy and daily living with MS.

These results can be used to develop targeted psychological and social support and interventions and hence help improving the social-emotional QoL for persons with MS.

Keywords. Multiple sclerosis, quality of life, gender comparison, intercultural comparison, coping with MS, coping with stress, psychological and social aspects of MS.

Kurzfassung

Multiple Sklerose (MS) ist eine entzündliche Autoimmunerkrankung des zentralen Nervensystems. Im Verlauf der Krankheit kommt es zur Demyelinisierung der Nerven, was zu physischen und kognitiven Einschränkungen führen kann. Wenig erforscht sind psychische und soziale Faktoren, die mit der Erkrankung und Einschränkungen durch diese einhergehen. Um dies zu verbessern, beschäftigt sich die vorliegende Dissertation mit psychischen und sozialen Faktoren im Zusammenhang mit der Lebensqualität von Menschen mit MS. Ich beleuchte sowohl Geschlechtsunterschiede als auch interkulturelle Unterschiede zwischen Österreich und den USA bezüglich ihrer Lebensqualität, Persönlichkeit und empfundener positiver Veränderungen durch MS. Außerdem lege ich Schwerpunkte auf die Rolle von sozialer Unterstützung und betrachte ob, und welche positiven Lebensveränderungen sich bei Betroffenen seit Diagnosestellung aufgetan haben.
Methode: Die interkulturelle Studie wurde sowohl in Österreich als auch in den USA mit je 64 freiwilligen TeilnehmerInnen durchgeführt, um interkulturelle Vergleiche anstellen zu können. Die Gesamtstichprobe von 128 Befragten setzt sich aus 78 Frauen und 50 Männern im Alter zwischen 20 und 57 Jahren zusammen. Ich erhob sowohl mit einem quantitativen Fragebogen als auch in qualitativen Interviews Informationen über die Lebensqualität, Bewältigungsstrategien und Stress. In der quantitativen Datenanalyse kontrollierte ich die vier Kovariaten Alter, das Ausmaß der Behinderung, MS Dauer und höchste abgeschlossene Ausbildung, um mögliche Einflüsse aufgrund der gewählten Stichprobe zu vermeiden.
Ergebnisse: Österreichische TeilnehmerInnen zeigten im Vergleich zu amerikanischen TeilnehmerInnen höhere Werte bezüglich ihrer sozial-emotionalen Lebensqualität. Amerikanische TeilnehmerInnen wiesen einen höheren Selbstwert als österreichischen TeilnehmerInnen auf. Des weiteren konnte ich zeigen, dass Frauen höhere Werte in der Fähigkeit Liebe auszudrücken, aufweisen als Männer. Unabhängig von Geschlecht und Nationalität berichteten TeilnehmerInnen von positiven Veränderungen und empfundenen Vorteilen durch MS. Diese Vorteile beziehen sich speziell auf Empathie, Achtsamkeit, verbesserte Familienbeziehungen sowie persönliches Wachstum. In den qualitativen Interviews fand ich interkulturelle und Geschlechtsunterschiede in Krankheits- sowie Stressbewältigungsstrategien. Zusätzlich zeigten sich interkulturelle und Geschlechtsunterschiede bei Erfahrungen mit MS und Erwartungen sowie Wünschen im medizinischen Kontext.

Diese Ergebnisse zeichnen ein klares Bild, in welchen Bereichen Verbesserungen der psychologischen und sozialen Unterstützung erforderlich sind und können bei der Entwicklung von psychosozialen Interventionsstrategien herangezogen werden.

Acknowledgments

Pursuing a doctoral thesis does not have a lot in common with being an undergraduate student, and I believe it does not have a lot in common with a regular job either. It is an all-in job with long hours and weekends spent for data collection, data analysis and writing the thesis. But it also gives you more freedom to pursue your ideas than any other job does, and it gives you the chance to meet many, as it was in my case, interesting and inspiring people with MS. A lot of people and institutions contributed directly or indirectly to this thesis. Here I want to give them proper credit.

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Chapter 1

Introduction

This thesis investigates psychological and social aspects of quality of life (QoL) in persons with Multiple Sclerosis (MS). MS patients often experience a diminished quality of life due to the progression and the symptoms of the illness. There are, however, factors not directly related to symptoms of the disease that affect the emotional and social quality of life with MS, and there are ways to help improve QoL that are complementary to treatment of disease progression and symptoms.

In this thesis, I elicit these factors contributing to QoL in MS patients to eventually enable more targeted therapies, to identify missing pieces in the support network and to build the foundation for understanding all psychological and social aspects of this disease.

1.1 Health and Illness

Before focusing on MS in detail, I will discuss health and illness in general. Aaron Antonovsky[3] describes factors that support health, rather than factors that cause disease. His model deals with the relationship between health, stress, and coping. He introduces the term 'salutogenesis', which expresses that health, respectively illness are not static terms, that they should rather be understood dynamically. He describes health as a continuous variable, which he calls 'health-ease versus dis-ease continuum'. The bio-psycho-social model of illness[22,82] describes the relation between body and mind. In the process of becoming ill always both aspects—body as well as mind—have to be taken into consideration to cover all details of the illness[22]. According to this model, illness sets in when the organism can no longer provide the autoregulative competency to cope with symptoms and disbalances.

The World Health Organization (WHO) defines **chronic illness** as a persistent or otherwise long-lasting condition in its effects, or a disease that manifests over time[85]. Figure 1.1 summarizes factors affecting chronic illness based on analyses of various authors (e.g., Newman et al.[55] or Anderson et al.[2]). Besides aspects of the *body* (such as physical symptoms, genetics, prior illnesses, gender, age) aspects of the *individual* (such as lifestyle, stress level, income, coping styles, social support) play a role in chronic illness. Furthermore the importance of *society* (such as health care, state insurance, or state support) have to be taken into consideration when thinking of chronic illness.

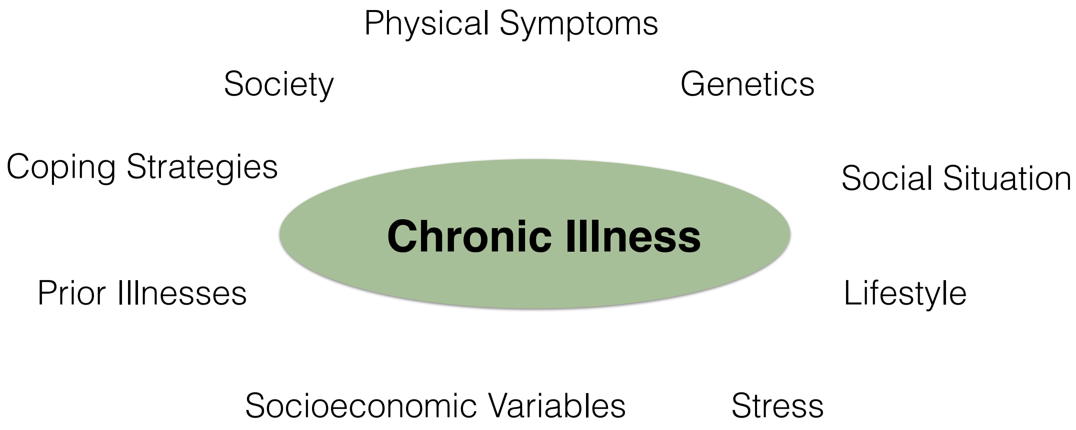

Figure 1.1: Variables affecting chronic illness.

1.2 Goals and Objectives of this Thesis

My goal is to draw a picture of MS as a whole and to look beyond the negative physical aspects. By focusing on different aspects of personality I want to elicit the current situation of affected and identify aspects of their mental health that could be improved, such as self-esteem, or the ability to express love. I investigate current needs and challenges of affected to eventually enable customized social and emotional support.

As more women than men suffer from MS, little research is available about what it means to be a man and have MS. In this thesis I investigate differences in the psychological and social context between women and men with MS using a large sample of both women and men. Additionally I am interested in differences between cultures, specifically between two regions (Austria and New England in the United States of America) with a similar standard of living, yet different cultures and health care systems.

I focus on the topics psychological and social QoL, aspects of mental health, perceived benefits from MS since being diagnosed, and the role of social support. I want to understand the social and emotional situation of MS patients and have a closer look at different aspects of living with MS. To get deeper insights in living with MS, I interviewed the affected about their experiences with MS, their needs and expectations. Additionally I asked questions about their coping strategies for dealing with MS and with stress.

My overall goal is to describe what persons with MS want and need and which challenges are accompanied by the illness. My work should enable the development of customized psychological and social support, which should be available to them starting with the day patients are diagnosed. By looking at differences in gender and nationality, this thesis can draw a broad picture of MS. Identifying similarities as well as differences in gender and nationality can widen the range of understanding MS globally.

1.3 Background on Multiple Sclerosis

Multiple Sclerosis (MS) is an inflammatory auto-immune disease of the central nervous system. Nerve fibers of the central nervous system are demyelinated through inflammation. This leads to many impairments, physical and cognitive, as well as psychological and social. The onset of MS is most often seen in young adults, mainly between 20 and 40 years[77]. The etiology of this disease is unknown, although many factors seem to influence its onset. A complex interaction between genetic and environmental factors is expected to cause this disorder. What is known is that women are affected approximately twice as often as men and the MS prevalence varies with geographical location. Asia, Sub-Saharan Africa, or South America, show a low disease incidence. In contrast, a higher frequency is observed between 40 and 60 degrees northern and southern latitude, such as in Northern and Western Europe, parts of the Northern USA, New Zealand, Canada, Russia, or South-East Australia[63].

The most common clinical signs and symptoms are sensory disturbance of the limbs, visual problems, such as double vision or loss of vision, motor dysfunction of the limbs, and gait difficulties[77]. The four clinical phenotypes of MS are *relapsing-remitting MS*, (about 80% of all cases at diagnosis), *primary progressive MS* (about 10-20%), *progressive relapsing MS*, (rare) and *secondary progressive MS*, to which about half of the patients with relapsing-remitting MS convert[77]. While previously the diagnosis was considered confirmed after several episodes, diagnostics using magnetic resonance imaging (MRI) is now state of the art[77].

Currently, there is no cure of the disease, but medical treatments for the suppression of the inflammatory process and the severity of its resulting symptoms are available.

Multiple Sclerosis in Austria and the US In Austria the prevalence of MS is estimated to be 98.5 per 100.000 people (8.150 affected), with similar rates in other countries in Central Europe[6] as of 2002. According to the Austrian MS Society OEMSG there are about 12.500 affected in Austria in 2013[57].

In addition to the impact on the personal lives of the affected and their families, MS also has a societal impact. The main factor in this regard is the loss of the patients' productivity. While at the onset of the disease about 75% continue to be in regular employment, this figure drops to about 8% at the usual retirement age in Austria[35]. According to Zwibel et al.[86] MS affects approximately 400.000 people in the US, with a prevalence of about 90 per 100.000. Globally, about 2.1 million are estimated to be affected[86].

Mathis et al.[45] point out that high costs result from the disease, in a direct and an indirect sense. Direct costs include medical costs associated with the course of the disease. Indirect costs result of the consequences of the disease, e.g., the inability to stay in the work force. Indirect costs are estimated at about 47.000 USD annually per patient[45]. To minimize the costs, the authors suggest to start medication treatment as early as possible, improve therapy adherence, facilitate the access to medication, and reduce the copay for medication and treatment.

Living with Multiple Sclerosis For the patients a diagnosis of a chronic illness, such as MS, often changes their lives in a very short period of time. This experience is often followed by a psychological and social breakdown as well as doubt in life and previous decisions that always appeared correct beforehand for the affected. It imposes many losses for the affected persons as well as for their social surrounding. The illness often requires a complete reorganization of the patient's life, which to them sometimes appears to be the hardest thing. Maintaining satisfaction in life often seems impossible. Not only is the quality of life in general affected, but especially living with the uncertainty about the disease progression influences the psychological well-being. Psychological and social disruptions in employment, sexuality, family life, routine activities, financial difficulties, and social isolation are further challenges patients have to deal with, all of them undermining their self-esteem[30].

Nevertheless, after the first breakdown following the diagnosis of a chronic illness, many affected report positive changes in their life. Not only do they find sense in life again, maybe even deeper and in a more conscious way, they also report having found benefits in their disease and the resulting life changes. Searching for and identifying benefits in the illness experience helps to restore meaningfulness, purpose in life, order, and a redefined self[61].

In general it is important to take into consideration that the disease is a conglomerate of symptoms followed by physical as well as psychological and social consequences. Therefore multiple comorbidities, i.e., additional disorders, go along with the diagnosis of MS. Because of that it is very important to understand the life of affected, their QoL, as the affected perceive it.

1.4 Sociological Concept of Gender

For interpreting the results presented in this thesis it is important to understand the different meanings of gender and sex. Gender describes the sociological context, the social and cultural meanings of femininity respectively masculinity. It describes what role expectations and obligations are predominant in different cultures and societies for women and men. Sex describes the biological differences between women and men[84].

1.5 Contribution and Collaboration Statement

The majority of this thesis was developed individually. In addition to guidance by my advisors, I received organizational support from the institutions where the survey was conducted. The results of this thesis were accepted as an abstract and presented as a poster at the American Academy of Neurology Annual Meeting 2015 in Washington, DC[40].

Chapter 2

Related Work

In this chapter I discuss previous work on psychological and social factors related to chronic diseases and MS in particular. First, however, I give a more detailed introduction into MS.

2.1 About MS

Factors related to the onset of MS A number of environmental factors, including, for example, geographic and seasonal factors, as well as genetics, are suspected to play a role in the cause of MS[77]. As causal agents, a viral infection is suspected. However, it is unlikely that only one single agent causes MS[77]. Besides biological and environmental causes, psychological and social aspects are considered relevant[41].

The Course of Multiple Sclerosis As previously mentioned, in *relapsing-remitting MS (RRMS)* relapses, i.e., a spontaneous appearance of symptoms, cause a decline in health status, from which patients can, but do not automatically have to, recover. In *primary progressive MS (PPMS)* the disease progresses without relapses and patients suffer a continuous decrease of their health status. *Progressive relapsing MS (PRMS)*, a rare form, describes a course of steady worsening of the disability with occasional relapses. *Secondary progressive MS (SPMS)* describes the progressive state to which many patients convert from RRMS over time[77].

The progression of physical symptoms of MS is commonly classified according to the Kurtzke Expanded Disability Status Scale (EDSS)[38] with scores from 0 to 10, where 0 corresponds to a normal neurological exam, 5 to impairments influencing daily activities and 10 to death by MS.

Prognostic Factors in Multiple Sclerosis About 70% of all patients suffering from MS are women[77]. Bergamaschi[11] points out that gender plays an important prognostic role, which suggests a possible involvement of female hormones at the onset of the disease. Furthermore the author points out that the age of onset of the disease has a prognostic character, where a younger age at the onset is related to a better prognosis. The type and combination of symptoms at onset are also relevant to prognosis, as an onset with multiple symptoms is related to poorer outcomes. A key tool for diagnostic and prognostic purposes is MRI (Magnetic Resonance Imaging). Diagnosis differ in the number, volume and location of lesions as well as the amount of loss of brain volume (atrophy); more and larger lesions and high atrophy are associated with worse outcomes. Additionally the author mentions variables during the course of the disease for prediction. Among other criteria he mentions short inter-attack interval times and the number of relapses. Several studies have indicated that a poor prognosis is related to male gender, high age at onset, and many attacks immediately after onset[11]. Rojas et al.[68] analyzed gender differences in atrophy and lesion load in MS in South America. They found that in the course of MS women and men differ in their brain volume. At the baseline women did not differ from men concerning their brain volume. Over a course of six years men showed a decrease of the general brain volume as well as the neocortical grey brain volume and an increase in lesion load. Women with MS showed a decrease of the neocortical grey brain volume.

Genetics, Hormones and Multiple Sclerosis According to the National MS Society (NMSS)[51] hormones may determine susceptibility to the disease, which may also explain the skewed gender ratio. Garcia-Montojo et al.[24] analyzed DNA of MS patients and found that the DNA copy number of human endogenous retrovirus-V (MSRV-Type) is higher in MS patients in comparison to the control group. Furthermore, women with MS showed a more elevated load of MSRV than women from the control group, and women show higher loads than men. The authors additionally could show that the increased number of MSRV is not only correlated with gender but also with the severity of the disease. EDSS rates were higher among women with an elevated MSRV load.

Tillack et al.[78] analyzed gender differences in neutrophil extracellular traps (NETS). NETS are networks of extra-cellular fibers. They mainly consist of the DNA of neutrophils, which are responsible for binding invading pathogens, mainly infections. The authors summarized that women show a higher systemic neutrophil count than men. As neutrophil counts correlate with estradiol levels during menstruation and pregnancy it is suggested that sex hormones influence neutrophilia. Tillack et al. showed a gender difference in circulating NETS, which could be a reason for the differences between women and men concerning the different course in MS, as men generally experience a more severe course of the illness.

Dominguez-Mozo et al.[20] analyzed the role of two toll like receptors (TLRs). TLRs are proteins and activate immune-cell responses against invaders. The authors especially focused on the two TLR9 single nucleotide polymorphisms. They compared persons with MS with a control group as well as genders within the groups. They found no relationship between the two TLRs, but an association for both with gender of the MS group. One variant (the AT haplotype) of TLR9 was found to be significantly higher in women than in men with MS. Furthermore, a lower severity among women was found than among men. Additionally, a trend towards a lower severity of the disease and a lower MRI disease activity with a lower gadolinium-enhancing lesion load was found to be related to the AT haplotype of TLR9, the most prevalent among women.

Epidemiology and Multiple Sclerosis Alcalde-Cabero et al.[1] compared the European incidence in MS from 1985 to 2009. They found that after 1985 the incidence of MS ranged from 1.12 to 6.96 per 100,000 persons across European countries. The incidence was higher in women, tripled with latitude and doubled with the study midpoint year. The authors point out that the North of Europe showed increasing trends from the 1960s and 1970s, with a historic drop in the Faroe Islands. Fairly stable data was identified in the period of 1980-2000. The incidence rose in Italian and French populations in the period 1970-2000, in Evros (Greece) in the 1980s, and in the French West Indies in around 2000. In summary, there was an increase in the incidence of MS in Europe between 1985 and 2009, for both, women and men.

Treatment of Multiple Sclerosis As MS is currently incurable, medications target the reduction of frequency and severity of acute episodes[64]. Therefore a number of immunomodulating substances are offered. According to the National MS Society[52], the following disease modifying medications are currently approved by the US Food and Drug Administration (FDA) for the indication MS in the US market. They are offered in form of infusions, subcutaneous or intramuscular injections, as well as oral capsules and are listed with their brand name (generic name), their distributor, their route of delivery and their FDA approval year.

- *Aubagio (teriflunomide) by Genzyme, a Sanofi company* pill taken daily orally, FDA approval in 2012.
- *Avonex (interferon beta-1a) by Biogen Idec*: intramuscular once a week, FDA approval in 1996.
- *Betaseron (interferon beta-1b) by BayerHealthCare Pharmaceuticals Inc.*: subcutaneous every other day, FDA approval 1993.
- *Copaxone (glatiramer acetate) by Teva Neuroscience*: subcutaneous, daily, FDA approval 1996.
- *Extavia (interferon beta-1b) by Novartis Pharmaceuticals, Corp*: subcotaneous, daily, FDA approval 2009.
- *Gilenya (fingolimod) by Novartis Pharmaceuticals, Corp*: capsule taken daily orally, FDA approval 2010.
- *Novantrone (mitoxantrone] by EMD Serono, Inc./Immunex Corporation*: four times a year by IV infusion, FDA approval 2000.
- *Rebif (interferon beta-1a) by EMD Serono, Inc./Pfizer, Inc*: subcutaneous three times a week, FDA approval 2002.
- *Tecfidera (dimethyl fumarate, formerly called BG-12) by Biogen Idec*: capsule taken orally, twice a day, FDA approval 2013.
- *Tysabri (natalizumab) by Biogen Idec*: every four weeks by IV infusion, FDA approval 2006.

A common treatment for a severe MS attack is the intravenous delivery of high-dose corticosteroids to reduce the inflammation and its consequences. Lutterotti et al.[43] tested the output of treating MS patients by autologous peptide coupled cells. This therapy should stop the strong autoimmune response in MS and avoid severe side effects as in other MS treatments. From the blood of patients mononuclear immune cells were extracted. These cells are then attached to peptides, which show wrong reactions in the brain in the course of MS. The result of these chemical interventions are then injected to the patients. They were able to show in their phase 1 trial that persons treated by peptide-coupled cells had a decrease in antigen-specific T-cell responses and that they were well tolerated by patients.

As Miller et al.[48] point out, prior reviews show positive effects of different types of MS-treatment (for example interferon-beta) on health-related quality of life issues. In their study, the authors compared MS patients receiving the MS medication Natalizumab with a placebo group concerning its effects on health-related quality of life. Based on these results the authors suggest to include health-related quality of life issues in MS patients' therapy, as MS has a strong impact on employment status, social and family relationships, sexual satisfaction, pain, fatigue, enjoyment of life, vision, bladder/bowl control, cognition and emotional well-being. These aspects may also affect therapy adherence, which shows that inclusion of health-related quality of life instruments is also important in improving outcomes in the clinical practice.

2.2 Quality of Life and Multiple Sclerosis

Figure 2.1 summarizes variables affecting the QoL in persons with MS as described by the literature discussed in the following.

Benedict et al.[10] analyzed different methods to predict quality of life in MS by taking

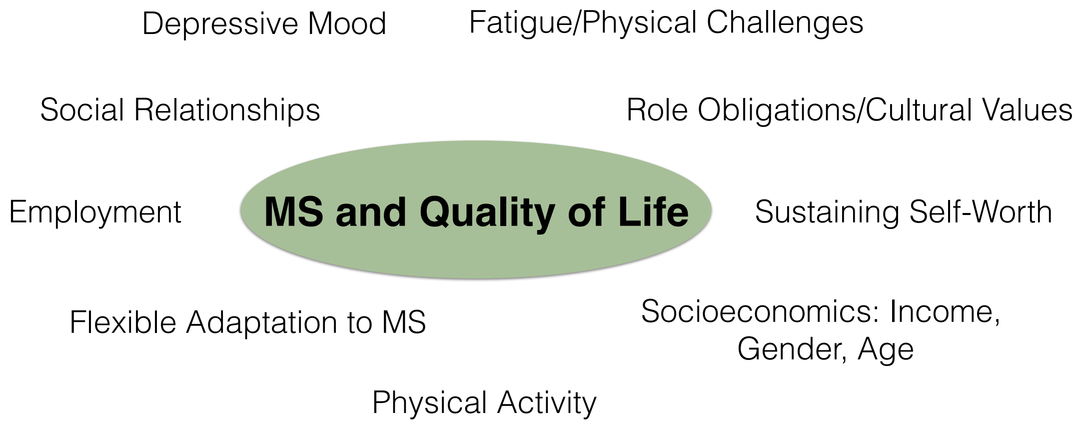

Figure 2.1: Variables affecting Quality of Life in Multiple Sclerosis

into consideration. They found that self-report health-related quality of life is most strongly predicted by measures of depression, whereas the employment status is predicted best by objective measures of cognitive function. The measurement of health-related quality of life is subjective and depends on the patient's happiness. It also correlates highly with different depression scales. This is in contrast to cognitive aspects that better predict what MS patients are capable of doing physically.

Baumstarck et al.[7] summarize the importance of measuring quality of life in patients with MS. They discuss that the term quality of life is a wide ranging construct. The authors' review show that in addition to physical variables, quality of life includes cognitive, emotional, social, and psychological well-being. Additionally, socio-demographic variables should be taken into consideration in the construct of quality of life.

Many different instruments try to quantify quality of life. The problem is that some questionnaires are too long to be used in real life applications and/or are not sensitive to changes in quality of life in patients over time. As a consequence, it is difficult for physicians to choose adequate instruments, although measuring quality of life in MS, beside only quantifying the physical changes, appears to be of great importance. Gold et al.[27] evaluated quality of life instruments in MS and validated the Hamburg Quality of Life Questionnaire HAQUAMS. This questionnaire is a reliable instrument for measuring QoL in MS. The questionnaire consists of 38 questions on the subscales 'Sensory Symptoms', 'Fatigue/Thinking', 'Vision', 'Mobility/Lower Extremities', 'Mobility/Upper Extremities', 'Bladder/Bowel/Sexuality', 'Social Function', 'Mood', and 'Handicap'.

2.2.1 Fatigue

Lobentanz et al.[42] took a closer look at factors influencing the quality of life in MS patients. They compared 504 MS patients with healthy individuals. The authors found that disability as well as fatigue and reduced sleep quality primarily influence the physical quality of life. Depressive mood was identified as the main factor influencing perceived quality of life.

Fatigue is an extremely prevalent issue for persons with MS. As Penner et al.[62] point out, fatigue has a great impact on persons with MS, negatively affecting quality of life and often being the reason for early retirement and unemployment. The authors show that reliable measuring of fatigue is difficult as it needs to be separated from other causes, such as depression, sleep disorders, or side-effects of medication. To manage fatigue in MS, pharmacological as well as non-pharmacological options are offered and the right management has to be decided based on the needs of the person. Krupp et al.[37] point out that some interventions, including medication, physical activity, or cognitive behavioral therapy, show some reduction of fatigue in MS patients.

Sauter et al.[69] adapted the English version of the six-week training on fatigue management by Packer et al.[26] to German and conducted their survey in Austria. They tested effects of a six-week training course for energy conservation for MS patients. The goal was to encourage active decision-making and to extend the use of the patients' available energy. The training included supervised practical activities and homework assignments. Participants learned, for example, about the importance of rest and time management. Additionally, participants had to keep a diary and rate their level of fatigue. The results after the fatigue management show an improvement in cognitive and physical scores. Furthermore, the subjective sleep quality improved and the depression score decreased to a normal level. The positive effects were still present after 7-9 months. Ghahari et al.[26] investigated the effectiveness of online and face-to-face fatigue self-management programs for adults with neurological conditions. They identified great improvements through the fatigue management program.

2.2.2 Physical Activity

As was shown by Stroud et al.[76], regular physical activity positively affects the level of fatigue, depression and quality of life in persons with MS compared to persons without regular exercise.

Tysza et al.[79] had a closer look at the relationship of health promoting behaviors, the participation in life roles, and health-related quality of life in women with MS. The authors showed that health-promoting behaviors (e.g., improved nutrition, stress management, physical activity, positive interpersonal relations, spiritual growth) have positive consequences for women with MS, raising their health-related quality of life. The authors therefore suggest to involve health-promotion in occupational therapy treatment.

As Kayes et al.[34] found out using qualitative semi-structured interviews with ten persons with MS, the decision to engage in physical activity is complex. Different factors influence the motivation to exercise. Examples are prior experience with physical therapy, the course of the disease, pre-conceived opinions about physical therapy, and emotional responses to successes and failures.

2.2.3 Gender and MS

Social role obligations and cultural values render the experience of a disabling illness different for women and men. Women with MS seem more resistant to depression than men and make different adjustments to the disease. For example, they are much more likely to move from full-time to part-time work when accommodating themselves to their illness, whereas men tend to either stay in full time work or give up work completely[28].

Kalb et al.[33] summarizes that the employment status plays an important role in the quality of life of persons with MS. There is also a big gender difference regarding employment. Men with MS are more likely to be employed than women. In the context of gender differences and employment in general[25], it can be pointed out that employment has a different meaning for women and men. More than a fifth of employed women aged between 30 and 64 in Germany in the year 2008 were employed part-time. The data is different for men: men are frequently employed full-time and less frequent than women do part-time work. According to the gender data report of Germany[19], men more often have paid jobs than women. For unifying family and employment, part-time employment often appears to be the solution for women. Women often have problems to return to their job directly after maternal leave. Reasons for that are missing child care options as well as a lack of flexible working hours.

2.2.4 Sustaining Quality of Life

Murray[54] interviewed two chronically ill patients, one woman with MS and one man with Hodgkin's disease, about changes they experienced since suffering from the disease. She points out that after a chronic disease is diagnosed patients begin to spend more time in *kairos*—a sense of soul-satisfying time. In this time-perception, patients begin to see life in cycles with different time lines running simultaneously. In contrast, the Greek word *kronos* describes a linear time perception, oriented on clocks and schedules. Time perception of patients differs from time perception of, for example, physicians. For patients time is perceived in terms of recurring 24 hour days appearing in recurring, small events, as, for example, the regular appearance of hospital staff, the arrival of meals, or going to sleep in the hospital etc.

In semi-structured qualitative interviews, Reynolds et al[65] talked to 27 women with MS, trying to find out about subjective experiences with quality of life and MS. In many cases several years after diagnosis had to elapse before these women were able to successfully construct positive ways of interpreting their illness experience. The women described strategies to gain quality of life: consciously looking after their health, maintaining meaningful occupations, maintaining their roles in society, establishing relationships, and figuring out their beliefs, aspirations, and philosophy of life. Furthermore the interviewed women pointed out strategies to maintain their quality of life: being active on disability issues, consciously valuing positive life experience, and finding benefits in adversity. But also negative aspects of living with MS were described, especially frustration, anger, and sadness, not only experienced because of the physical symptoms of MS, but also resulting from social exclusion and other disabling forces. Many women described that living with MS is learned in a variety of different ways and that it is a process, that coping is never static.

Irvine et al.[31] conducted a semi-structured focus group interview with seven MS patients concerning subjective life experience. Results show that patients not only pointed out difficulties, identity struggles, uncertainties, and challenges through MS, but also new ways of adaptations, positive changes, and adjustment. The results of Irvine's focus group interview shows that the diagnosis was met with negative reactions. The majority also had regrets about leaving paid employment, which goes beyond a reduced income, leaving patients with less structure and self-worth. Furthermore women reported that they missed being able to wear high heels, indicating a loss of femininity.

Charmaz[16] dealt with the question of loss of self in chronically ill and talked in her qualitative interviews to 57 chronically ill, including MS patients. She found that patients experience a high level of uncertainty in their life and their future, having to deal with former self images they have lost. Additionally, greater dependence on others, also for monitoring their self image in others' eyes, strains relationships. Bonds to others weaken and isolation and loneliness become more central. Furthermore, the author points out that in the course of the illness, chronically ill become more restricted, which makes it harder to maintain social relationships. Losing the ability to do something makes it hard to sustain a meaningful life, giving one the self-worth needed on his/her own.

Kralik et al.[36] investigated the transition in sexual self-identity for women living with multiple sclerosis. The authors talked to women in group sessions as well as on one to one interviews at home. Important topics were the changing importance of sexuality in their lives, sexual desires, reaction of others, having a responsive and participating partner, their appearance (looking good), confidence and self-esteem. In the interviews it was shown that affirmation from others was central to shaping self-identity. As the authors point out, shifts in self-identity when suffering from MS can create overwhelming tension in different aspects of women's lives and it is very important for caregivers as well as affected to understand these shifts for being able to adapt and carry on.

Boeije et al.[12] point out that the continuity of one's biography since body and performance failures lead to the loss of salient aspects of the self. The authors talked to 22 people with MS who live at home in an advanced stage of MS. It was pointed out very frequently that they had to give up everything. Additionally, as the course of MS is unpredictable for affected, many participants found it impossible to set new directions in lives.

Audulv[4] identified different self-management patterns for dealing with a chronic disease. In 81 qualitative interviews, chronically ill were interviewed about their self-management strategies. Audulv found four patterns of self-management with a chronic illness and participants often used more than one pattern simultaneously. A 'consistent pattern' includes, for example, managing the long term medication, an 'episodic pattern' includes, for example, managing exercise. An 'on demand pattern' was pointed out to be necessary to manage crisis related to the health situation and a 'transitional pattern' includes managing changes due to the illness.

Moss-Morris et al.[50] tested the effectiveness of a cognitive behavioral intervention compared to supportive listening led by nurse therapists. The authors point out that high levels of emotional distress were reported by patients with MS, in addition to higher levels of anxiety, poor quality of life, and difficulties with social functioning and relationships. The results of Moss-Morris[49] show that cognitive behavioral interventions are more effective than supportive listening to reduce distress. The cognitive behavioral therapy consisted of eight sessions and nine chapters, held face-to-face respectively conducted by telephone. They mainly focused on strengths and difficulties and coping of the participants. Homework had to be completed between the sessions. For their main support person a manual on coping strategies for persons living with MS patients was offered and participants could bring their main support person to a session. After the intervention, the cognitive behavioral group was significantly less stressed in comparison to the supportive listening group. Patients with poor social support respectively a high stress level benefited of the cognitive behavioral intervention even more.

Wagner et al.[81] analyzed the effects of classical cognitive behavioral therapy face-to-face in comparison to an internet-based guided self-help support in persons with bulimia nervosa. The authors found no difference between both ways of offering guidance.

Rintell et al.[67] asked 54 persons with MS in focus groups about their experience and important aspects in mental health care they received. The authors summarized that affected want mental health care interventions directly after the diagnosis. Furthermore they want an ongoing screening for problems in this area. Additionally they pointed out that they are gladly receiving mental health services in their MS-center and that the inclusion of family members in treatment was very beneficial for them.

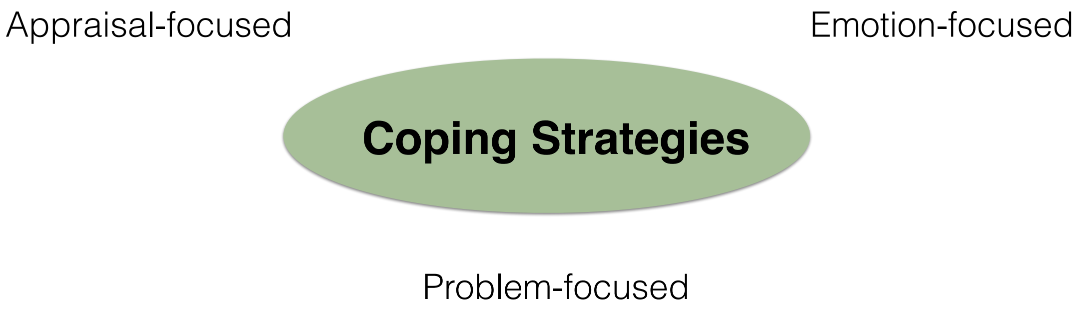

Figure 2.2: Coping styles, based on work by Weiten et al.[83]

2.3 Coping

Figure 2.2 gives a general overview of coping strategies, based on the analysis by Weiten et al.[83]

Weiten et al. describe three different coping styles[83]. The first are **appraisal focused** strategies which are about modifying the way of thinking. Examples for these strategies are denial, or distancing oneself from the problem, or more generally, redefining goals and values. **Problem focused** strategies include reducing respectively eliminating the stressor and adapting to the situation. **Emotion focused** strategies include trying to change the own emotional reaction to the stressor, distracting oneself, managing hostile feelings, meditating or relaxing.

Matud et al.[46] identified differences in stress coping styles between women and men. The authors point out that women listed family and health-related events more frequently as stressors than men, whereas men listed relationship, financial, and work-related events more often than women. Women showed emotional and avoidance coping styles more often and pointed out less detached coping styles than men. Men showed more emotional inhibition than women. Women showed higher values on somatic symptoms and psychological distress. The authors conclude that the female stress coping style is more emotion-focused, whereas the male stress coping style is more rational and detached.

As Mund et al.[53] show, repressive coping is associated with somatic disease. Repressive coping behavior was measured by the discrepancy between reporting answers to emotional stimuli or stressful tasks and the measured physical reactions. As Mund summarizes, multiple studies showed that repressive copers show pathologically high blood pressure and an increased risk for cardiovascular diseases as well as for cancer, asthma, and diabetes. The question of causality remains open, i.e., it is unclear whether repressive coping is a consequence of the disease or the disease a consequence of repressive coping.

2.3.1 Coping with Multiple Sclerosis

Figure 2.3 illustrates positive coping strategies recommended for dealing with MS. How these coping strategies were identified is described in the following.

Hellige[30] researched approaches for dealing with the diagnosis MS, on how to integrate

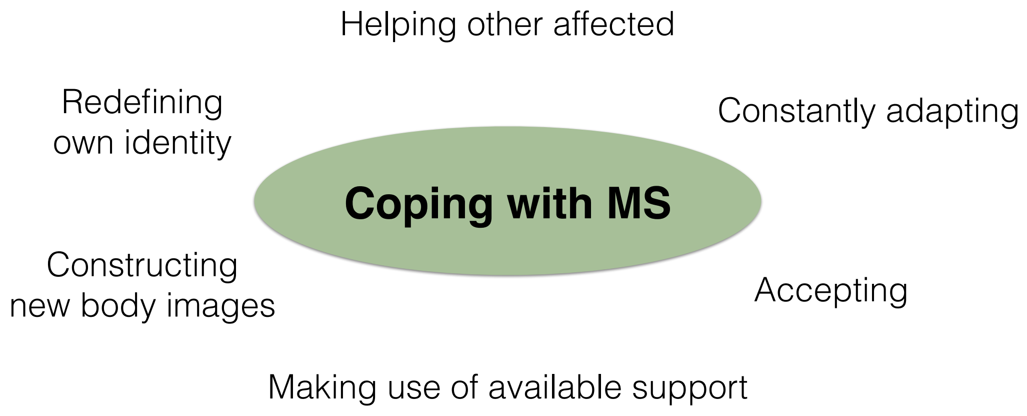

Figure 2.3: Overview of Coping Styles used in MS

and accept the disease. Based on *Grounded Theory*[74], Hellige interviewed patients about self and body image, the process until receiving the diagnosis, ways of a self-determined living, and knowledge about the disease. She found that it is important for patients to define their own trajectory and that they are aware of their personal influence, as this helps planning their life and improves their quality of life. As the author points out, health literacy and an understanding of the own capacity is a precondition for experiencing quality of life. By health literacy, Hellige primarily means being aware of the available support systems and treatment options while considering them critically.

As Corbin et al.[17] point out, dealing with a chronic illness requires constant adaption to newly appearing health issues and continuously integrating the new health changes in ones life. These adaptations are not only required in a physical and social, but also in a psychological context. As the body fails and function or performance is reduced in the course of a chronically illness, examination of the own identity and its continuous redefinition is necessary. This requires reconstructing the self-image and accepting the changes taking place as a consequence of the disease. Affected are forced to redefine their present and future and say good-bye to former images constructed for the own life and construct new body images. In the course of chronic illness perceptions of a disrupted body image are caused by

1. the inability to execute certain kinds of physical activity,
2. the bodily appearance,
3. the physiological body functions.

Therefore, as Corbin et al. point out, it is of importance to provide affected with support in the process of redefinition and acceptance to prevent a total breakdown.

Rintell et al.[66] describe psychosocial preventive interventions in MS and showed the importance of integrating family members in the process of having MS. In three different meetings, family members were encouraged to talk about their perception of changes within the family since MS was diagnosed. They also received medical information on MS. Family collaboration was promoted and a take-home workbook was given to the family members, where psychosocial aspects of MS are described and resources for support are listed. To enable such groups in the future, Rintell et al. developed a leaders' guide for healthcare professionals.

2.4 Personality and Mental Health

Fazekas et al.[23] point out that adult attachment and temperament do not contribute in the clinical variability of early MS. Personality factors such as the adult attachment style and temperament do not have an impact on physical aspects of the disease respectively relapses.

Strober et al.[75] investigated the role of personality and unemployment in MS. The authors found that the severeness level of the disease, the personality characteristic of persistence, and the information processing speed were strong predictors of the employment status.

2.4.1 Emotion

As LaRocca et al.[39] point out in their book about understanding cognitive challenges in MS, cognitive changes appear in affected in the course of MS. Besides great anxiety regarding potential cognitive decrease when having MS, it has an emotional and social impact on the affected.

Kalb[32] deals with the emotional and social aspect of cognitive changes in MS. She points out that depression affects cognitive ability independent of having MS. In case of MS it appears even more important to work on depression with affected to reduce cognitive problems. It is very important to inform patients that cognitive changes do not have to be severe for all patients and that cognitive changes do not mean losing the capacity to remember, but it commonly affects attention, speed of information processing, and expressiveness (e.g., finding words). Cognitive changes can be clearly assessed and treatment is offered. Patients can also learn how to manage and compensate for their cognitive changes and adapt to them in daily life.

Furthermore, Kalb et al.[33] discuss the emotional and psychological impact of relapses in MS. Every relapse is a change in life for affected as well as their families. Kalb points out grief, anxiety, anger, and guilt as normal emotional reactions to such an event. These feelings follow a relapse, before productive adaption to the new physical and cognitive status and integration of the losses can start. They also point out that for many patients the physical status returns to normal after a first episode, which leads to denial and sometimes even refusal to use disease-modifying medications. After the second relapse people have to start accepting that they suffer from a chronic disease, which forces them to adapt their life to the new situation. For some affected the way from denial to hopelessness is very fast. According to Kalb reflecting the meaning of the words 'control' and 'independence' is important, as is accepting the situation and accepting help. Patients think of the loss they suffer, the life they had, the self they lived. They reduce their activities as a consequence of not being able to do things they once could.

Additionally Kalb points out that after relapses the feelings of grief, anxiety, anger, and guilt not only are experienced by patients with MS, but also by the whole family. Having MS is a great challenge for spouses as well. Communication about the own feelings, especially in such situations, appear to be an important coping strategy, as Kalb mentions. Further challenges may be changes in physical intimacy, possibly caused by sexual dysfunction, incontinence, fatigue, the increased amount of care necessary, etc. Cognitive impairments or depression may also hinder couples in planning for a future together.

Kalb also discusses the impact on children of MS patients, who also experience the relapses of their parent. They might think it is their fault that the parent had a relapse. Children in general are afraid of hospitalization of their parents and wonder whether their parents still can care for them. Furthermore, children are common targets of their parents' emotional overload.

Also, grown-ups with MS who used to live independently from their parents for years, often have to return to their parents' house to receive care. This appears challenging for both sides. Parents, which expected their children to offer them care as they age have to accept the new situation as well.

Schwarz et al.[72] showed that in persons with MS high levels of depression correlate with severe fatigue. They found that fatigue was found to limit social-, work-, and overall role performance, but not physical role performance. The authors conclude that persons with MS who feel that they can choose or create environments suitable to their psychological or physical conditions report less global fatigue and less fatigue-related distress.

Buchanan et al.[13] asked 100 young adults with MS about their main experienced changes through suffering MS concerning emotions, feelings and mental health. 35% reported feelings of depression and hopelessness. 37% pointed out the need for the treatment by mental health professionals for a personal or family problem during the last 12 months. Only 59% of them actively searched for help.

2.4.2 Cognition

John DeLuca[18] summarizes the current knowledge on cognitive changes in MS. He points out that 50% to 66% of MS affected suffer some level of cognitive problems. Patients with MS show mainly problems with working memory, which consists of the short term storage (for example to store number 3 and number 5) and the mental manipulation of the stored information (for example when asked to add 3 and 5). This is the process that keeps information active or in mind. Additionally DeLuca summarizes that MS patients have difficulties with the anterograde memory, meaning acquiring and remembering new information since suffering MS. As optic neuritis, the inflammation of the optic nerve, is a common symptom of MS, vision problems make processing information difficult. About one quarter of persons with MS have difficulties with their visual perception. Several studies show that patients with MS show a slower information-processing speed than healthy people. Furthermore, DeLuca points out that people with MS show problems in executive functions such as solving complex problems. This may result from difficulties in planning, organization, and/or reasoning and conceptualization. Word finding difficulties—the 'tip of the tongue' phenomenon—are common in MS. Problems with word fluency, for example, listing words that start with a specific letter, are common. These difficulties are, however, mostly mild to moderate.

As MS is very different in every individual, symptoms vary widely. Not every person with MS shows cognitive problems. But it has to be taken into consideration that even a mild cognitive problem may have a severe impact on the quality of life of persons with MS, their employment status, their ability to drive, or the effects on self-confidence and self-esteem. In addition DeLuca talks about the importance of taking care of secondary factors of MS. While primary factors of cognition describe the direct impact of neural damage on cognition, secondary factors describe dynamic factors, which can change daily (such as depression, fatigue, stress, side effects of medications, lack of sleep, physical activity, different life experiences). The author points out that affected with MS should have a closer look at their own secondary factors and how they affect their daily life. Observing which parts of their life (work, leisure time, communication) are affected is an important step for taking responsibility for the own situation. Both, primary and secondary factors affect the experience of cognitive efficiency. This has to be taken into consideration when thinking of improving quality of life.

2.5 Benefit Finding in Multiple Sclerosis

In 2005 Pakenham[58] investigated benefit finding in MS and asked affected as well as their care-givers about seven different topics related to benefit finding in a qualitative study. He examined the direct and stress-buffering effects of benefit finding on positive and negative outcomes. In his study two dimensions, *personal growth* and *family relations growths* were identified. In 2008 Pakenham studied sense-making in MS[60]. He identified sixteen sense-making topics, which he extracted from qualitative interviews. The *Carer-Sense-Making Scale*[59] includes six psychometrically sound factors:

- catalyst for change,
- acceptance,
- spiritual perspective,
- incomprehensible,
- relation ties, and
- causal attribution.

The findings have implications for the measurement of sense-making. Pakenham continued his research and developed the Benefit Finding in Multiple Sclerosis Scale (BFIMSS)[61]. In this questionnaire he focuses on different areas, in which affected could have found benefits since being diagnosed MS. This scale measures seven different factors concerning adjustment since having MS. These factors are:

- compassion/empathy,
- spiritual growth,

- mindfulness
- family relations growth,
- lifestyle gains,
- personal growth, and
- new opportunities.

Pakenham points out that the term benefit finding can be interchangeably used with post-traumatic growth or stress-related growth.

As Barskova et al.[5] discuss, persons with a severe respectively chronic disease report positive changes in their life since suffering from the illness, a phenomenon called post-traumatic growth (PTG). The authors mention that this effect is known for cancer, HIV/AIDS, cardiac disease, multiple sclerosis, and rheumatoid arthritis. Concerning personality characteristics and PTG it was pointed out that optimism, higher perceived self-efficacy, and extraversion may be associated with the experience of more growth-related changes and consequently may facilitate the process of disease adjustment.

The emergence of mindfulness in benefit finding was unique in the Benefit Finding in Multiple Sclerosis Scale[61]. According to Pakenham, mindfulness may be unique to chronic illnesses. Having tested the factors of the BFIMSS concerning their reliability and stability it can be concluded that all factors as well as the whole scale is psychometrically sound.

2.6 Social Support and Multiple Sclerosis

Liu et al.[41] describe the relationship between psychosocial factors and the onset of MS. The authors compared 41 persons with MS (26 women and 15 men) with 41 persons without MS in the control group (similar in age, gender and educational level). They measured psychosocial differences in life events, in personality, in social support as well as in subjectively perceived symptoms as consequence of psychological or physical impairment. They identified significant differences between the MS group and the control group not only concerning their negative symptoms and emotions (such as depression, anxiety, obsession, phobia, tense interpersonal relationships, and somatization disorder), but also in the total number of negative life events, their family problems and the utilization of social support. Persons with MS showed higher values on the scales testing these items in comparison to persons without MS. The results suggest that the emotional instability and introverted personality of patients with MS led to the occurrence of negative emotions. Additionally, the authors suspect that the occurrence of negative emotions was related to negative life events experienced years before they were diagnosed MS, especially the impact family problems brought about. As many kinds of negative emotions in the MS group correlated negatively with the utilization of social support, the authors suggest that the patients lacked the ability to use social support, which can usually reduce it. As a consequence, the risk of incidence could increase when an individual is under stress without social support. Based on the study results, the authors speculate that a lack social support, intense psychological stress, and the resulting immune responses might lead to

MS. The authors conclude that psycho-social factors are closely associated with the onset of MS and may play important roles in the development of the disease.

Chapter 3

Research Questions

The goal of this thesis is to research the emotional and social quality of life in persons with MS and have a closer look at differences in gender and nationality in this context. Additionally I am interested in strategies to process, integrate, and cope with MS as well as with stress. I focus on coping strategies, differences between women and men, as well as on cultural differences. Furthermore I take a closer look on benefit finding since being diagnosed MS as well as on personality variables and how they are connected with quality of life in persons with MS. Last but not least I investigate the role of social support in MS. The following assumptions are formulated based on the literature review discussed in the previous chapter.

Quality of Life

QoL-1: Women and men suffering from MS differ in their social-emotional quality of life.

QoL-2: Austrian and US MS patients differ in their social-emotional quality of life.

QoL-3: Women and men suffering from MS do not differ in their perception of their health status.

QoL-4: Austrian and US MS patients do not differ in their perception of their health status.

QoL-5: Social-emotional quality of life correlates positively with the BFIMSS subscale *mindfulness.*

QoL-6: Social-emotional quality of life correlates positively with the BFIMSS subscale *new opportunities.*

Coping with MS and Stress

CaS-1: Women and men suffering from MS differ in their coping strategies for dealing with the illness.

CaS-2: Affected from Austria and the US differ in their coping strategies for dealing with the illness.

CaS-3: Women and men differ in their coping strategies for dealing with stress.

CaS-4: Affected from Austria and the US differ in their coping strategies for dealing with stress.

Personality and Mental Health

PMH-1: Women and men with MS differ in their self-esteem.

PMH-2: Affected from Austria and the US differ in their self-esteem.

PMH-3: Women and men with MS differ in their ability to love.

PMH-4: Affected from Austria and the US differ in their ability to love.

PMH-5: Perceiving a purpose in life correlates positively with self-esteem.

PMH-6: Self-esteem correlates positively with social-emotional QoL.

PMH-7: Ability to love correlates positively with social-emotional QoL.

Benefit Finding in Multiple Sclerosis

BFiMS-1: Positive changes in life since being diagnosed MS are perceived by persons with MS independent of gender and nationality.

Social Support

SoSu-1: Women and men with MS do not differ in their received level of social support.

SoSu-2: Affected from Austria and the US do not differ in their received level of social support.

SoSu-3: Having social support correlates positively with self-esteem.

SoSu-4: Having social support correlates positively with the ability to express love.

SoSu-5: Having social support correlates positively with the BFIMSS subscale *mindfulness.*

SoSu-6: Having social support correlates positively with the BFIMSS subscale *family relations growth.*

Living MS

LiMS-1: Affected women and men differ in their expectations in the medical context, their health literacy and their experiences in living with MS.

LiMS-2: Affected from Austria and the US differ in their expectations in the medical context, their health literacy and their experiences in living with MS.

Chapter 4

Methods

4.1 Survey and Sample

The data elicited to support this study is based on two legs of a survey, one of which was conducted in Graz, Austria, the other one in Boston, Massachusetts in the United States of America. The survey includes responses from 128 voluntary participants, 78 of whom were women and 50 were men.

In both countries, the Institutional Review Board (the Ethics Committee) approved the study. A written study information sheet (see Appendix A) was given to the participants and the procedure and study details were explained to them orally. Participants were informed that their refusal to participate had no consequences for their continuing treatment respectively the relationship to their doctors and that participation was voluntary. After that, participants were asked to read the informed consent form (both, the Austrian and the US version are included in Appendix A), ask clarifying questions, and provide their signature to express consent.

To keep the survey situations as similar as possible and to exclude interviewer biases, all interviews were conducted by the same person, who speaks both languages fluently. The survey used self-report questionnaires as well as qualitative interviews, which were recorded with permission of the participants. The survey in Austria was conducted in a neuro-rehabilitation clinic near Graz (Klinik Judendorf Strassengel) which has dedicated facilities for treating MS patients. The survey in the USA was conducted at the the Beth Israel Deaconess Medical Center (BIDMC) in Boston, MA, in the neurology department which also focuses on Multiple Sclerosis. The US sample includes the same number of persons and the same demographic structure in terms of gender.

The clinic in Austria focuses on the neuro-rehabilitation of MS patients and participants were recruited from the in-patient pool. The US sample at Beth Israel Medical Center was recruited from the out-patient pool. Inclusion criteria for the participation were **age** (20-57 years), and a **clinically definite MS diagnosis** (including MS types such as relapsing remitting, primary progressive or secondary progressive). Additionally I **avoided a strongly unbalanced gender ratio** and only included participants with the **cognitive ability to complete the questionnaire and participate in the qualitative interview**.

4.2 Survey Procedure

In both countries, the survey took place in a quiet, undisturbed surrounding in the clinic. Both, the quantitative questionnaire and the qualitative interview combined were scheduled to last approximately thirty minutes. The questionnaire was filled-out while the survey investigator was present, to enable participants to ask clarifying questions. In cases where participants were not able to physically complete the questionnaire they were assisted by the investigator. The qualitative interviews were recorded and transcribed.

4.3 Survey Preparations

4.3.1 Pretest

To test whether the survey material is appropriate a pretest was conducted with three persons with MS, two men and one woman, aged between 29 and 39, on Dec. 5, 2011. The pretest showed that it is more appropriate to start with the quantitative questionnaire followed by the qualitative interview, as it was easier for participants to structure their answers and follow a central thread in the qualitative interview when having already filled out the quantitative questionnaire. The pretest also indicated that approximately half an hour was adequate to carry out both, the quantitative questionnaire and the qualitative interview.

4.3.2 Main Surveys

The main survey in Austria started in December 2011 and last until October 2012. 64 persons with MS, 39 women and 25 men, aged between 20 and 57, participated voluntarily in the survey. In the US, the survey was conducted between May 2013 and November 2013. When help was needed, the investigator read out the questions and marked the answers given on the questionnaire. The qualitative interview took about 15 minutes for most patients. Some talked very slowly due to their MS symptoms, while others went into great detail in their answer, which led to some variety in the total duration of the interview. One person in Austria refused to be recorded. In this case, the interview was transcribed manually during the ongoing interview.

4.4 Instruments

The quantitative part of the survey, reproduced in both English and German in Appendix B, contains parts of three questionnaires dealing with personality, quality of life, and benefit finding since being diagnosed MS.

The first part of the questionnaire is made up of two scales of the TPF (‘Trierer Persönlichkeitsfragebogen’)[9], specifically the *sense of self-esteem* scale and the *ability to love* scale. This questionnaire is originally German and was translated into English and translated back into German. Backward translation involved re-translating the questionnaire into the original language by an independent party to verify its correctness.

The second part of the questionnaire includes parts of the quality of life questionnaire *HALEMS 10.0/HAQUAMS*[27] and is originally German. The subscales *social function*, *mood*, and *handicap* were used in the questionnaire[27]. The HAQUAMS is available and validated for both English and German, hence no translations were necessary for this part.

The third part of the questionnaire is the *Benefit Finding in Multiple Sclerosis Scale (BFiMSS)* by Pakenham and Cox[61]. This questionnaire asks for benefits found since being diagnosed MS and is originally in English. The questionnaire was forward and back translated to German for the Austrian leg of the survey using the same procedure described above.

At the end of the quantitative questionnaire I asked questions eliciting socio-demographic data, such as living situation, income, level of education, employment status, gender, age, and more.

The quantitative part was followed by a qualitative interview, where 26 questions were asked. These questions are reproduced in both English and German in Appendix C. They dealt with the topics *self perception*, *living with MS*, *health literacy*, *subjective perception of the illness*, *health-related questions*, *questions relating to quality of life*, and *social support.*

According to Hamilton[29] a gender bias describes that even when a person intents to express something gender-neutral but uses masculine generics, the gender content of the imaginary of the person is not gender-neutral. To avoid this, both, the quantitative and the qualitative questionnaires were formulated in a gender-inclusive way.

4.4.1 Quantitative Questionnaire

In the following I provide a detailed description for the different parts of questionnaires used in the survey.

The quantitative personality inventory TPF ('Trierer Persoenlichkeitsfragebogen') by Becker[8] consists of nine subscales including 120 items. The nine subscales are:

- behavior control,
- mental health,
- sense in life versus depression,
- selflessness vs. self-centeredness,
- free of symptoms vs. nervousness,
- expansiveness,
- autonomy,
- self-esteem, and
- ability to love.

This inventory measures two aspects of personality: mental health and behavior control.

As this survey focuses on psychological and social aspects affecting QoL in MS, and to keep the overall burden on participants low, only two scales—*self-esteem* and *ability to love*—of the TPF were used. These two scales consist of 23 items and focus on participant's self-esteem and appreciation of oneself and of others.

An example question of the self-esteem scale is 'I am ... convinced that it is very possible to like me'. All statements (items) in this part of the questionnaire had to be completed with the most appropriate word from the rating scale *always*, *often*, *sometimes*, and *never*. An example for the ability to love scale is 'I can ... express a lot of love towards another human', again using the same rating scale. For further details see the quantitative questionnaire in Appendix B.

The **Quality of Life questionnaire HAQUAMS**[27] evaluates the quality of life of persons with MS. It measures different aspects of quality of life and consists of 38 questions in total. I included 14 questions in the survey, which can be summarized in the QoL scales *mood*, *social function* and *handicap*. One additional question of the *bladder/bowl/sexuality* scale about sexuality was included. An example of a question asked is 'Communication about my illness is poor with my family'. The five answer options on the rating scale were *not at all*, *a little bit*, *somewhat*, *quite a bit*, *very much*. See Appendix B for details.

The **Benefit Finding in Multiple Sclerosis Scale**[61] includes 67 items constructed for persons with MS and eliciting their experiences as a result of having MS. The scale deals with questions structured in the seven subscales:

- empathy,
- spiritual growth,
- mindfulness,
- new opportunities,
- lifestyle gains,
- family relations growth, and
- personal growth.

In this case I used the entire questionnaire. One example for Pakenham's BFIMSS is 'I have become more spiritual'. The three answer options on the rating scale were *not at all*, *somewhat*, *a great deal*.

Socio-Demographic Questionnaire Socio-demographic data is important to consider when evaluating patient's health status. Marmot et al.[44] describe the importance of social variables on health equities. They point out that health inequalities are not limited to the most socially disadvantaged but health equity runs from the top to the bottom of society. Burkert et al.[15] show that socio-economic factors have influence on health parameters in the context of overweight and obesity. Burkert subsequently demonstrated the importance of socio-economic factors in the context of nutrition, lifestyle and health[14]. Furthermore Schwartz et al.[71] report on the varying contribution of demographic, medical, and social support variables in predicting the mental health dimension of quality of life among people with MS. Due to these results I decided to also ask for socio-demographic data.

The elicited socio-demographic data in the questionnaire includes gender, age, family situation (e.g., married, divorced), living situation (e.g., in a city, in a village), employment status (e.g., employee, unemployed), degree of employment (e.g., full-time, part-time), highest completed level of education (e.g., secondary school, university), monthly net-income (e.g., less than \$ 550, \$ 551 to \$ 850, etc.), the year of MS diagnosis, and the year of first symptoms.

For an adequate comparison of income between the US and Austria the income was normalized to adjust for costs of living. The Euro values were first transformed to the current USD value (with a course of 1 EUR = 1.32 USD as of July, 31st 2013) and then adjusted by cost of living factors according to the OECD values for June 2013[56] (Austria: 1, USA: 0.87). All amounts were rounded to the nearest ten.

Clinical Health Information The Expanded Disability Status Scale Score (EDSS)[73], which is routinely measured in MS care, was used to quantify the degree of impact of the disease on the patients. The EDSS scale[38] rates the neurological impairment of patients with MS. The scale ranges from 0 to 10, where 0 indicates a normal neurological exam and 10 means death related to MS, while 7 describes having to use a wheelchair. The score is recorded by medical professionals routinely and was available in both clinics. The clinics also provided additional medical history such as the type and progression of MS, as well as information about current and past medication.

4.4.2 Qualitative Interviews

The interviews included 26 questions, which are reproduced in Appendix C. The interviews were based on the approach of Hellige[30] and were conducted with the goal of collecting additional information that was not asked and is hard to ask in quantitative questionnaires.

The 26 questions were related to the following main topics. Participants were asked to elaborate on the answers.

- Self-perception (four questions). Examples are ‘In what respect would you wish to be different than you are?’, or ‘How do you cope with the realization that you are ill?’.
- Living multiple sclerosis (three questions), for example, ‘How do you cope with stress?’, or ‘How would you rate yourself—independent, having to rely on others, or somewhere in-between?’.
- Health literacy (eight questions), such as asking for health services used, negative experiences with health care personnel, or which sources of information about MS participants used.
- Subjective perception of the illness (two questions). One example is ‘What explanation do you have for contracting MS?’
- Health-related: ‘How well do you perceive your health?’

- Questions related to quality of life (five questions), e.g., to describe changes in life since being diagnosed MS, or describing the most significant experience resulting from MS.
- Social support (one question): ‘Who helps you when you are at your wits end?’

Through formulating open answers in the interview, participants had the opportunity to name specific views and interpretations. Through this, the subjective aspects regarding, especially, quality of life and social support were elicited. For example, while in the quantitative questionnaire two questions about social support were asked, the qualitative interview elaborated on this issue to understand who the supporting people are, and to enlighten the emotional aspect of social support.

By asking ‘How did you obtain your knowledge about MS?’, I elicited information about the instrumental aspect of social support. Additionally, by asking for ‘support services of the health care system’, I asked for the instrumental dimension of social support. Concerning quality of life I asked affected additional questions in the qualitative interview to get an idea what changes in QoL since having MS they experienced and how they feel about them.

4.5 Analysis Methods

I evaluated the quantitative data with standard statistical data analysis methods. The qualitative interviews were recorded and transcribed. I used an inductive approach whereby transcripts were coded in order to develop conceptual categories.

4.5.1 Quantitative Data Analysis

For analyzing the quantitative data I used a combination of methods. To give an overview of the distribution of responses and to describe the sample concerning its socio-demographic characteristics I used **frequency tables**. Additionally I also present means of different items/(sub)scales in frequency tables.

For constructing scales, I calculated **reliability analyses** with the reliability measure of **Cronbach’s Alpha**. Cronbach’s Alpha is a coefficient of internal consistency. It describes whether selected items measure the same construct. When Cronbach’s Alpha has a value higher than .6 the scale is considered as internally consistent. By using **factor analyses** I tested whether the items of the scales constructed describe the same construct (load on the same factor). I tested whether significant positive or negative correlations among items or scales exist using **partial correlations**. I point out the correlation coefficient r and its significance level p. I considered p-values < 0.05 as statistically significant and p-values < 0.10 as statistical tendencies.

With the **General Linear Model** a (multivariate) (co)variance analysis (ANCOVA) is calculated. In these calculations I analyzed differences between the **independent variables** gender and nationality, each two-factorial, and the **dependent variables** as QoL (sub)scales, personality subscales or benefit finding in MS subscales. I controlled **covariates** possibly influencing the effects in ANCOVA or correlations. I selected the four variables age, MS duration, EDSS (disability score), and educational status as covariates.

In partial correlations I additionally used gender and nationality as covariates. For all quantitative data analyses I used the software SPSS (version 20.0).

For calculating the MS duration the year of diagnosis was subtracted from the the year of the survey (2012 in Austria and 2013 in Boston).

To give an overview of particularities in types of life-situations of the participants, I calculated a **multiple correspondence analysis**. With this method types of life-situations with similar characteristics can be identified.

4.5.2 Qualitative Data Analysis

I summarized the answers given in the structured interviews in categories. I identified a wide range of information of the participants about coping strategies, health literacy, quality of life and social support. Additionally I took a closer look at the answer patterns along the independent variables gender and nationality. The qualitative data of 128 interviews included the possibility of multiple answers for each question. In the data analyses each category identified could contain up to the total N, as participants can answered in multiple categories.

Statements by Austrian participants are translated and the original German quote is presented in a footnote. The interview number, gender and nation is referenced in brackets: I52, m, US, for example, describes a quote from the interview with ID 52, in the US, by a man. When participants gave indifferent answers such as ‘I don’t know’, ‘no life events’, ‘no wishes, nothing is missing’ or ‘can’t think of anything’, they were not included in the analyses, as the main goal was to identify new categories and their frequencies.

4.5.2.1 Category Building

By asking open questions and letting persons answer whatever they wanted, I got a broad idea of what people were thinking. Although the interview questions were formulated beforehand and I asked every participant the same questions, the interpretation of the question was freely chosen by each participant. I summarized answers dealing with similar topics in a category and counted the number of answers in each category. Typically, I identified multiple categories per question.

4.5.2.2 Quantifying Answer Categories

I show the frequencies of categories as percentages, in most cases separate for gender and nationality. The percentages describe the relationship to the N of all persons having answered the question and the N of participants having answered in this category. For each category the total N describes all persons having answered this particular question. The N per question varies as some participants did not answer some questions. The number of categories identified varies per question, as different answers were given to each question.

4.6 Statistical Data Preparation and Constructing of Scales

It was necessary to construct different scales for evaluating the research questions. Items are put together in scales when they fulfilled the necessary criteria of a positive correlation with each other and a high reliability (Cronbach's Alpha coefficient). Missing values were replaced by substituting means of the items.

4.6.1 Personality Scales

For the study I used the two TPF subscales *self-esteem* and *ability to love*, including 23 questions. For constructing these two TPF scales I correlated the items of the scales and calculated Cronbach's Alpha. Based on the TPF guidelines[8] I coded the answers from 1 (never), to 2 (sometimes), 3 (often), and 4 (always). I controlled whether there were national differences in the Cronbach's Alpha value. As I could exclude this possible bias, I constructed the two scales. I did the same control for nationality for all other scales.

Self-Esteem Scale

As in the *self-esteem* scale all twelve items of the TPF questionnaire correlate positively with each other and show a Cronbach's Alpha of .86, I constructed the scale *self-esteem*. Low values on this scale imply a low self-esteem, high values describe a high self-esteem.

Ability to Love Scale

In the *ability to love* scale, I put eleven items about the ability to express love together. Their Cronbach's alpha scale value is over .77. For the scale construction three items had to be recoded, following the TPF manual. These three items were originally poled negatively, while all other items were formulated in a positive direction. The three items were 'My thoughts revolve around myself so much, that I have difficulties being emphatic with others', 'Expressing affection and tenderness is explicitly difficult for me' and 'I have problems with accepting other peoples' weaknesses and faults'.

4.6.2 Quality of Life Scales

I constructed the QoL scales based on the HAQUAMS subscales. I asked following subscales of the HAQUAMS in the questionnaire—*social function* (six items were asked, two had to be recoded), *mood* (six of the eight items were asked, four had to be recoded), and *handicap* (1 item). I calculated the Cronbach's alpha for these subscales. I also asked one additional item, belonging to a scale—*bladder/bowel/sexuality*—asking for the satisfaction with participant's sex life. High values on the HAQUAMS subscales indicate a high burden with MS (implying a low QoL). High values on the single item 'I am satisfied with my sex life' contribute to high QoL. On the single item *handicap* ('How far does MS affect your ability to live a normal life?') high values describe a high burden with MS (implying a low QoL). The five answer options ranged from 1 (not at all) to 5 (very much).

The five answer options for the *handicap* scale item 'How far does MS affect your ability to live a normal life' ranged from 1 (not at all) to 5 (very much), hence high values on this item imply a high burden and as a consequence contribute to a low QoL.

To evaluate the internal consistency of the two subscales *mood* and *social function* I calculated Cronbach's Alpha, which is 0.75 for the *Social Function* scale and 0.78 for the

Mood scale. This indicates that both scales are consistent and the items they include measure the same construct.

Social-emotional QoL Scale

I built a *Social-emotional QoL* scale over 13 items (*QoL mood scale, QoL social function scale, sex life satisfaction*), as all items correlate positively with each other. The Cronbach's Alpha of the social-emotional QoL is .835. The *mood* scale alone only includes six out of eight items of the HAQUAMS scale, as the HALEMS 10.0 was used for the Austrian survey. The HALEMS is the prodecessor of the HAQUAMS and asks some different questions. As a consequence it was useful to construct a social-emotional QoL scale.

Purpose in Life Scale

Purpose in life was measured with the single-item of the QoL scale 'I feel a sense of purpose in my life'. The scale ranged from 1 (not at all) to 5 (very much).

4.6.3 Benefit Finding in Multiple Sclerosis Scale

The *Benefit Finding in Multiple Sclerosis Scale* (BFIMSS) is a questionnaire with 43 items. It elicits whether there are aspects in which MS patients have found benefit since being diagnosed. For the results of the *Benefit Finding in Multiple Sclerosis Scale* I created seven subscales following the original BFIMSS questionnaire. When all items of the suggested subscale correlated positively and showed an adequate Cronbach's Alpha in both legs of the survey, the items were aggregated to the subscales. As can be seen in Table 4.1 all subscales of the BFIMSS show a Cronbach's Alpha of .65 or higher. The *Life Style Gains* scale shows the lowest internal consistency with a Cronbach's Alpha of .65, whereas the *Spiritual Growth* shows a high internal consistency with a Cronbach's Alpha of .89. Overall, these results indicate that the items of the subscales measure the same construct.

Subscales	**Cronbach's Alpha**	**Nr. Items**
Compassion	0.88	8
Spiritual Growth	0.89	4
Mindfulness	0.73	5
New Opportunities	0.77	6
Life Style Gains	0.65	6
Family Relatios Growth	0.67	5
Personal Growth	0.79	7

Table 4.1: Cronbach's Alpha for the BFIMSS subscales in this study. Cronbach's Alpha is a coefficient describing the internal consistency of a scale. The coefficient should be 0.6 or higher to describe an acceptable scale. As can be seen in this table all subscales have a Cronbach's Alpha of higher than 0.6. This means that all scales constructed are internally consistent. The table also describes the amount of items that were included for the scale construction.

These subscales measure aspects in the following seven areas:

- The subscale *compassion* contains eight items and include topics such as having become more helpful and empathetic towards others, or giving support and hope to others. Items asked on this scale are for example ‘I became more respectful of others’, or ‘I learned to communicate better with other people’.
- The subscale *spiritual growth* includes four items. They deal with having become more spiritual and having found new faith. Items of this subscale are, for example, ‘I have a better understanding of spiritual matters’, or ‘My faith has been strengthened‘.
- The subscale *mindfulness* contains five items dealing with having learned acceptance, slowing down and taking one day at a time. Examples are ‘I learned to slow down’, or ‘I became more accepting of others’.
- The subscale *new opportunities* contains six items dealing with having found new interests, a new path in life or having developed new relationships with supportive others. Examples are ‘I developed new interests’, or ‘I established a new path in my life’.
- The subscale *lifestyle gains* consists of six items dealing with re-evaluating nutrition, health and a balanced life style. Examples are ‘I re-evaluated my diet and physical activity’, or ‘I learned the importance of having a balanced lifestyle’.
- The subscale *family relations growth* includes five items dealing with having a better relationship with family and friends and becoming aware of the support of other people. Examples are ‘My friends and family worry about me more’, or ‘I kept in better contact with my family’.
- The subscale *personal growth* consists of seven items including becoming more independent, more positive and more courageous. Examples are ‘I have become more motivated to succeed’, or ‘I have developed greater inner strength’.

For answering these questions, the Lickert scale ranged from 1 (not at all) to 3 (a great deal). I excluded two items from the subscale calculations as they did not fit in the subscales concerning their intracorrelations and internal consistency. I excluded the items ‘My life has become less complicated’ from the mindfulness subscale and the item ‘I became closer to my family’ from the family relations growth subscale for the subscale calculations. The items did not correlate highly with the rest of the items of the subscale and reduced the Cronbach’s Alpha for the subscale. The German translation of the questionnaire show lower Cronbach’s Alpha values in comparison to the English speaking sample. While this could be random variation, it could also indicate that the questions were interpreted slightly different in the two versions of the study.

4.6.4 Social Support Scale

I calculated a social support scale with the two items of the HAQUAMS QoL questionnaire ‘I get support from friends or neighbors’ and ‘I get support from my family’. Both variables measure a supportive aspect of QoL and correlate significantly positive with each other. As a consequence I put them together into the *social support scale.* The answer options for these items ranged from 1 (not at all) to 5 (very much).

4.6.5 Health Status Scale

In the qualitative interview I asked participants to rate their health status on a scale from 0 (very bad) to 10 (very good).

Chapter 5

Sample Description

Here I give an overview of the distribution of the sample. I present the socio-demographic structure of the data, living-situation variables, and health data. I also compare the sample distribution between Austria and the US. In addition to these results I explain the covariates I selected for controlling possibly influential effects on the results. To get an overview of the sample and its socio-demographic structure, I describe the sample in detail comparing the various variables for the two countries Austria and the US.

5.1 Gender and Age

Both legs of the survey include exactly 39 women and 25 men aged between 20 and 57. While in the Austrian part 57.8% were between 40 and 49 years old, in the US part only 37.5% fell into this age group. The US sample was younger with 40.6% in the category 20 to 39 years in comparison to 20.3% in Austria. To account for this difference in the age structure between Austria and the US, I controlled age as covariate in the data analyses when calculating ANCOVAs or partial correlations. Detailed break-downs of the age/gender distribution for the two countries can be seen in Figure 5.1.

5.2 Family Situation

As can be seen in Figure 5.2, the biggest group of participants was married (36.5% in Austria, 53.2% in the US). More participants were divorced in Austria (15.9%) in comparison to the US (9.4%). Figure 5.3 shows that the largest part of participants declared to be the youngest among their siblings (Austria 45.2%, US 34.5%).

As can be seen in Table 5.1, the average age of the participants' mothers when giving birth to the participant is similar in Austria (M=27.81, SD=6.69) and the US (M=27.67, SD=6.31). The table also shows that the average number of children participants have is 1.35 in Austria (SD=1.23), and 0.97 in the US (SD=1.13). In Austria participants have on average 2.08 siblings (SD=1.68), in the US participants have on average 2.25 siblings (SD=2.01).

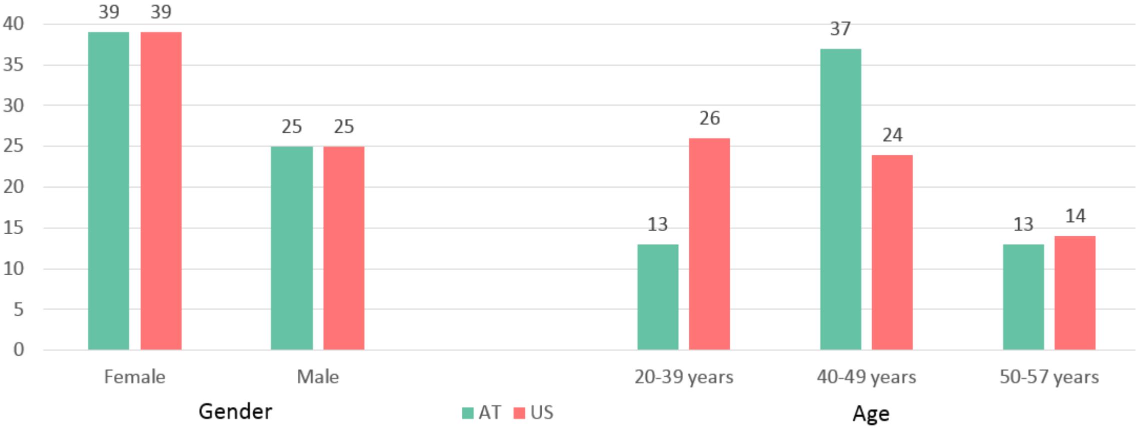

Figure 5.1: Gender and age in the United States and Austria. The mean age in Austria was 44.08 (SD=8), while the mean was 41.63 in the US (SD=8.64). Austria N=64, US N=64.

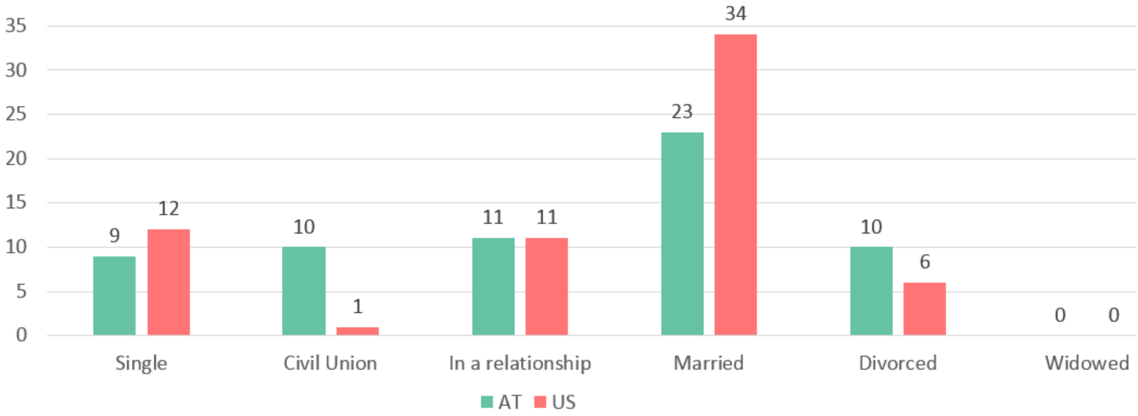

Figure 5.2: Family situation of participants. When combining civil union and marriage into a single concept, the samples are very similar. Austria N=63, US N=64.

	Austria				**USA**			
	N	Range	Mean	SD	N	Range	Mean	SD
Number of children	46	0-5	1.35	1.23	62	0-4	0.97	1.13
Number of siblings	63	0-8	2.08	1.68	64	0-11	2.25	2.01
Age of mother	57	17-48	27.81	6.69	64	15-41	27.67	6.31

Table 5.1: Number of children and siblings and mother's age at birth.

5.3 Living Situation

As can be seen in Figure 5.4, more than half of the participants live with their partner (62.1% in Austria, 68.3% in the US). In both countries participants live mainly in a city (Austria 45.2%, US 48.4%) followed by a municipality (Austria 37.1%, US 39.1%).

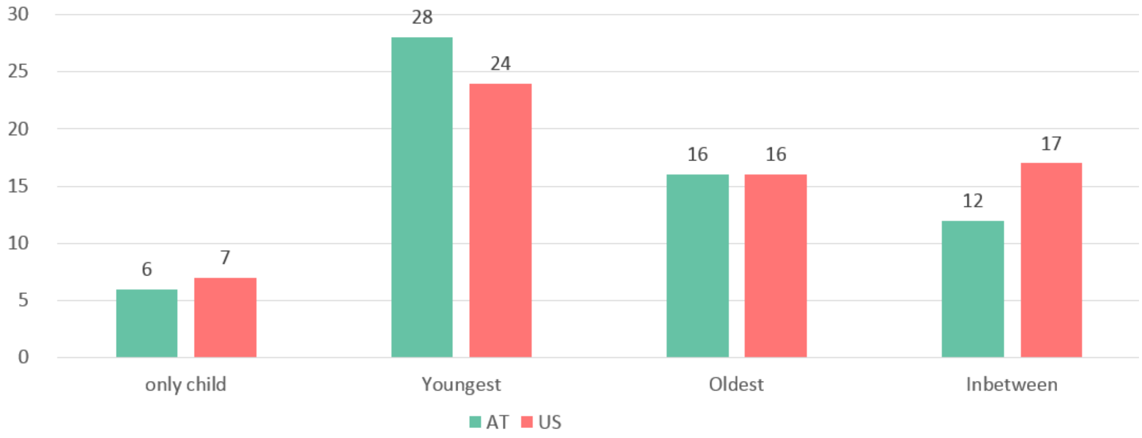

Figure 5.3: Birth position of participants. Austria N=62, US N=64.

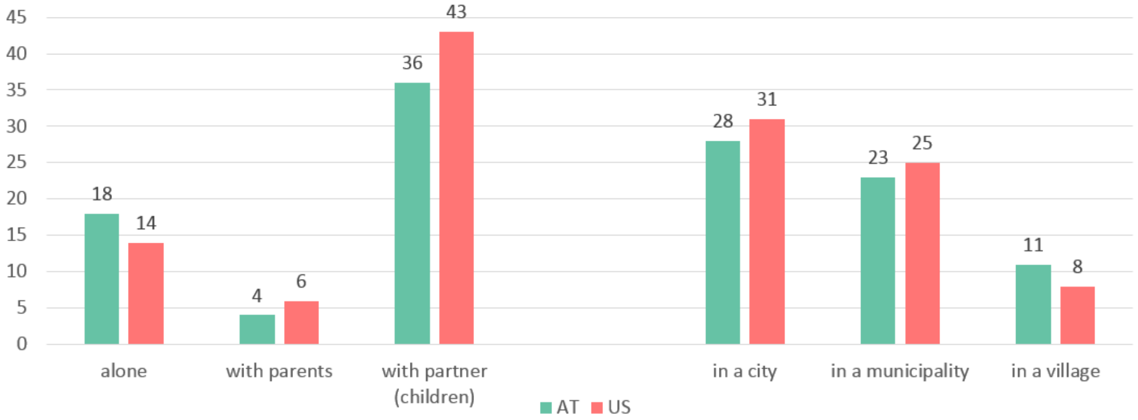

Figure 5.4: Living situations in Austria and the US. The left side shows who participants live with (Austria N=58, US N=63), the right side shows where they live (Austria N=62, US N=64).

5.4 Employment, Education and Income

Figure 5.5 shows that more than the half of the participants were retired due to health reasons in the Austrian sample (53.1%) which is true for 20.3% of US participants. The biggest group of US participants pointed out to be employees (48.4%) which was at 23.4% among the Austrian participants. Comparing the employment levels, it can be summarized that in Austria 18 persons were employed full time, while there were 27 people in full-time employment among the US participants, as shown in Figure 5.6. A closer look on the cross tabulation of EDSS and employment status reveals that 57.4% of participants with an EDSS score 0-2.5 (mild) were employees, while the majority of severely affected patients (EDSS 6.5 and higher) was retired due to health reasons.

Concerning education, 76.2% in Austria pointed out that their highest completed level of education was secondary education (i.e., they held a high school degree or similar),

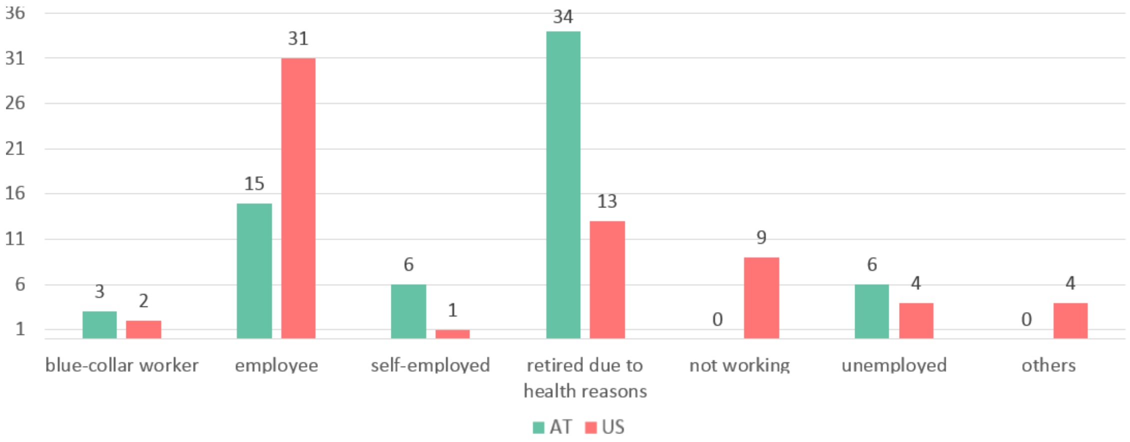

Figure 5.5: Employment status of participants in Austria and the US (Austria N=64, US N=64).

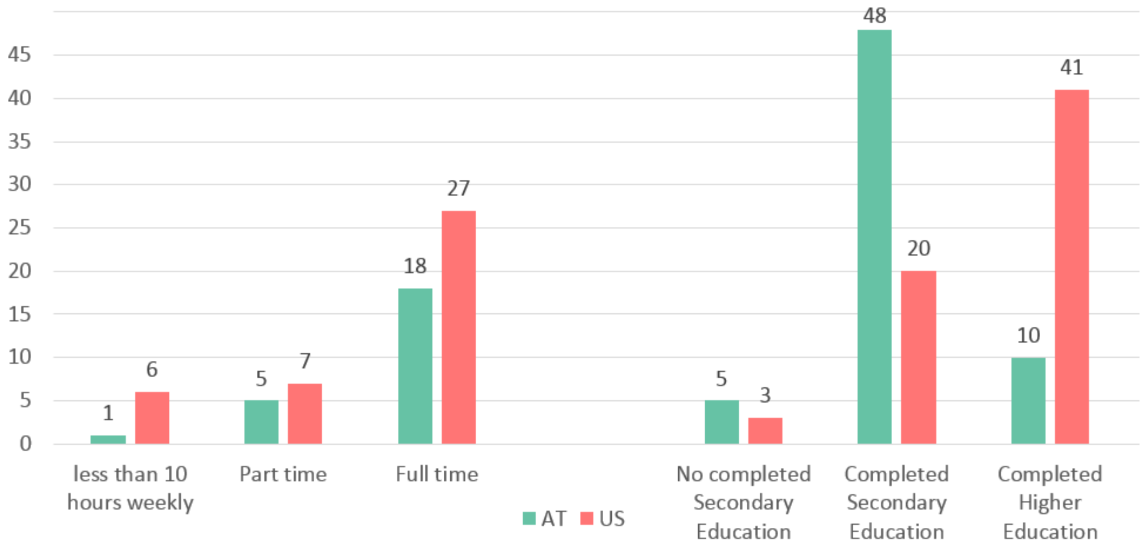

Figure 5.6: Amount of employment (Austria N=24, US N=40, note that these numbers exclude retired and unemployed participants) and highest level of education (Austria N=63, US N=64) of participants in Austria and the US.

while this proportion was at 31.2% in the US. The biggest group in the US (64.1%) has completed a higher education, such as a tertiary education (college or university), which is at 15.9% in Austria, as can be seen in Figure 5.6. Because of these differences I controlled for the educational level and used it as a covariate in ANCOVAs and partial correlations.

As can be seen in Figure 5.7 the biggest group in Austria with regards to monthly net income per person receives between 551 and 1.150 USD (30.6%), which was lower, at 16.4% for American participants. Note that these numbers are normalized to reflect purchasing power as explained in Section 4.4.1. 44.3% of US participants pointed out to have a monthly net income exceeding 2.300 USD, whereas only 9.7% among the Austrian

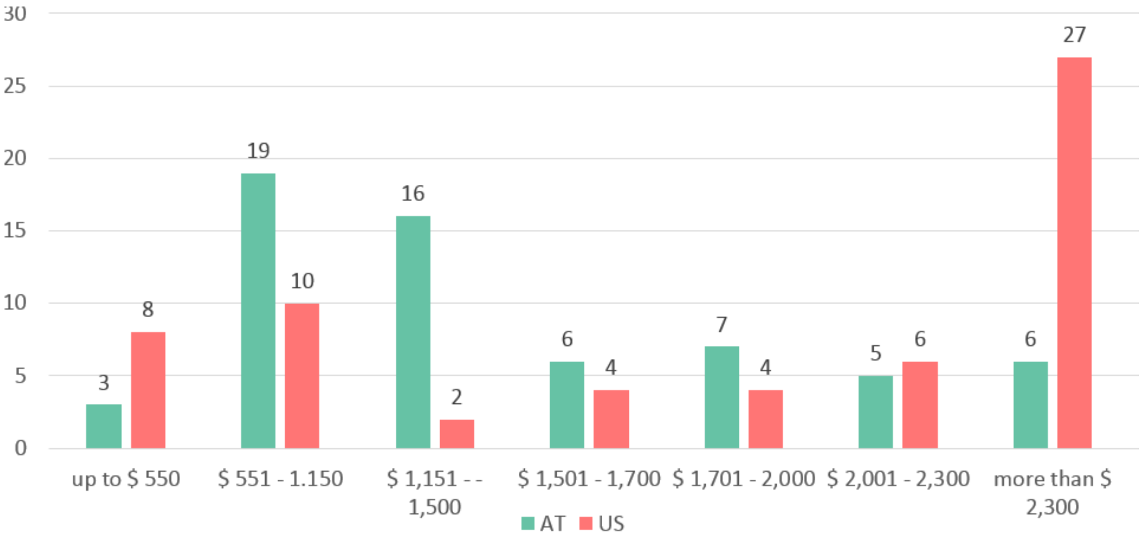

Figure 5.7: Net income of participants in Austria and the US. Austria N=62, US N=61.

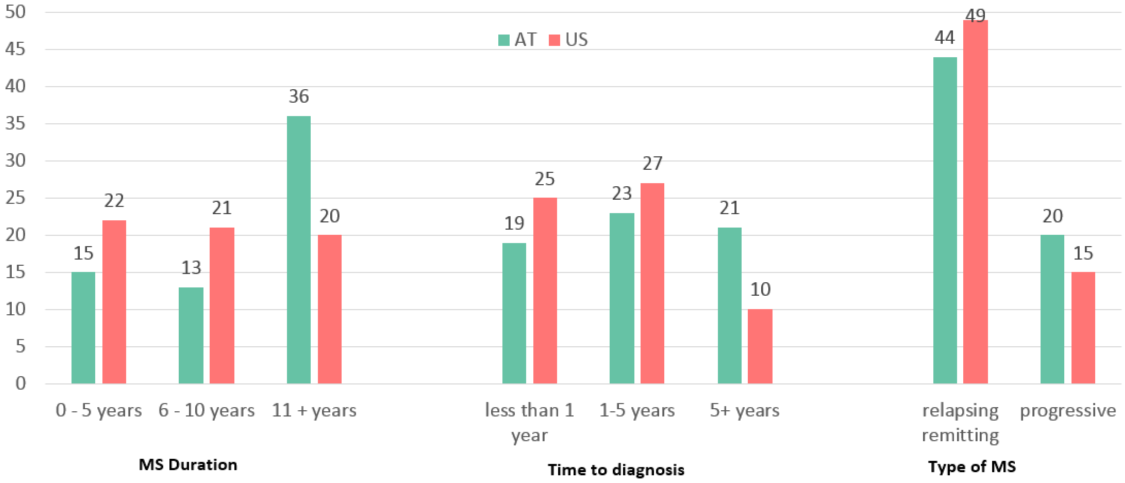

Figure 5.8: MS Duration (Austria N=64, US N=63), Time to diagnosis (Austria N=63, US N=62) and MS type (Austria N=64, US N=64) in Austria and the US.

participants are in that category. By investigating cross tabulations I identified that the biggest group of people with more than 2.300 USD of monthly income were employees (60.6%) while the biggest group of participants having monthly less than 550 USD were retired due to health reasons (27.3%) or unemployed (27.3%).

5.5 Health Variables

As can be seen in Figure 5.8, the biggest group of participants in Austria (57.8%) has had MS for eleven years or longer (31.7% for the US), while the groups in the US are rather evenly distributed among the three categories 0-5, 6-10, 11 or more years. The

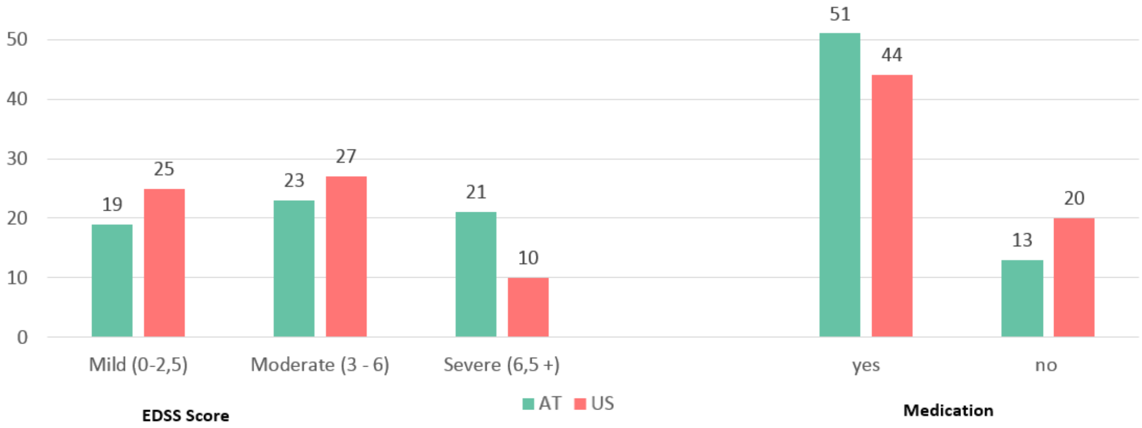

Figure 5.9: EDSS (Austria N=63, US N=62) and use of medication (Austria N=64, US N=64) in Austria and the US.

biggest group in the US had MS for 0-5 years (34.9%) in comparison to 21.9% of Austrian participants in this group. To not bias the comparison between countries, I controlled for this variable as a covariate in the statistical analyses. In Austria a third of the participants (33.3%) pointed out that more than five years passed in-between the appearance of first symptoms to being diagnosed, while this quota was at 16.1% for US participants. 50% of those that are 50 or older were diagnosed more than five years after they experienced first symptoms, which is likely due to the lack of imaging technology at the time those patients were diagnosed.

When comparing the MS types in both nations we can see that more than two thirds of the participants have a relapsing remitting MS type in both countries, with slightly higher values in the US, which is likely due to the higher average age in the Austrian sample.

As can be seen in Figure 5.9, in the US sample more participants had a mild form of MS with EDSS scores from 0 to 2.5 (40.2%), while only 30.2% of the Austrian participants had a mild form of MS. More Austrian participants (33.3%) had high EDSS scores (6.5 and higher) while this number was at 16.1% for US participants. Because of these differences I used the EDSS as covariate in the statistical analyses. In Austria, more participants received treatment for MS (79.7%) than in the US (68.8%). The main reasons pointed out for not receiving treatment were:

1. a lack of trust in the medication and therefore refusing treatment,
2. having no further medical treatment options available, or
3. having stopped medication because of being pregnant or having the desire to get pregnant.

More participants in Austria had mobility issues (Figure 5.10) and used assistive devices such as wheelchairs or walking canes (32.8%) in comparison to US participants (14%). In Austria 26.6% needed assistance when filling in the questionnaire (due to tremors, not being able to hold the pen, not seeing good enough), while in the US 10.9% needed such assistance.

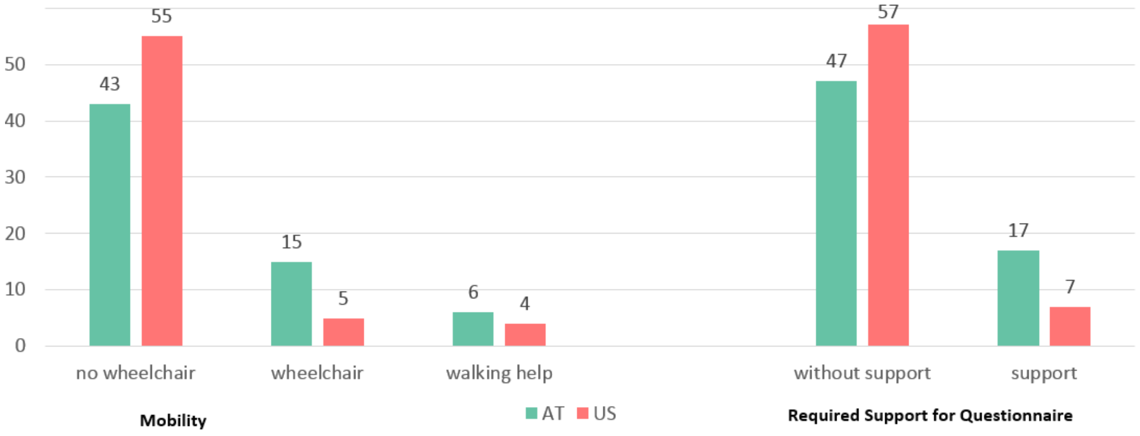

Figure 5.10: Mobility (Austria N=64, US N=64) and support for filling in questionnaires (Austria N=64, US N=64) in Austria and the US.

	N	Range	Mean	SD
Austria	58	1-10	5.72	1.91
US	64	3-10	6.88	1.25

Table 5.2: Perception of the health status on a scale from 1 (very bad) to 10 (very good). Austria N=58, US N=64.

Table 5.2 shows the differences in the responses between Austrian and American participants concerning their perception of the own health situation rated from 1 (very bad) to 10 (very good). In Austria the mean is 5.72 (SD=1.91), while the mean is 6.88 (SD=1.25) in the US. As a higher value describes a better perception of the own health status it can be concluded that Austrian participants perceive their health status lower than American participants which also reflects the differences in the EDSS scores of the samples.

Chapter 6

Results

In this chapter I present the results of the survey and evaluate the research questions postulated in Chapter 3. As previously stated, the focus of the study is to investigate gender and cultural differences in the context of psychological and social aspects affecting quality of life in persons with MS. Here I have a closer look at the social and emotional quality of life of affected, and focus on coping strategies for MS and for stress in general. In addition to that I look at two personality aspects 'self-esteem' and 'ability to love' of affected; benefit finding; and the role of social support.

When comparing the two factors gender and nationality I adjusted the calculations to the four covariates MS duration, EDSS score, age and highest level of education. In all partial correlations I used the six variables gender, nationality, MS duration, EDSS score, age and highest level of education as covariates. For details on the methods used see Chapter 4.

6.1 Quality of Life

I identified intercultural differences regarding the social-emotional quality of life, as Austrian participants perceived a higher social-emotional QoL with MS than American participants ($p<.10$). Additionally I identified significant cultural differences in the satisfaction with the sex life: Austrian participants are more satisfied with their sex life than US participants. Furthermore I found a statistical tendency ($p<.10$) with regards to differences between Austrian and US participants on the *perceived health status* scale. US participants perceived their health better than Austrian participants.

I identified no gender differences regarding social-emotional QoL and the perceived health status with MS. In the context of perceived health status I found that persons who perceived their health as rather good are typically only mildly affected by MS, indicating that participants have a realistic perception of their own health. Additionally I found that persons with a high social-emotional QoL also pointed out having found benefits in the context of 'mindfulness' and 'new opportunities' since being diagnosed MS. In the following I discuss these results in detail.

6.1.1 Social and Emotional Quality of Life

	p			Women		Men		Austria		US	
	gender	nation	g x n	M	SD	M	SD	M	SD	M	SD
mood	0.35	0.14	0.59	2.30	0.09	2.42	0.11	2.24	0.10	2.47	0.10
social function	0.78	0.18	0.45	2.14	0.09	2.10	0.11	2.01	0.11	2.23	0.11

Table 6.1: Results of QoL subscales 'mood' and 'social function'. Covariance analysis (calculated with two-factorial ANCOVA) of gender, nationality, and gender crossed with nationality (g x n) as p-values. The right side of the table shows means and standard deviations for gender and nationality on a scale from 1 to 5, where high values correspond to a low QoL.

To test whether women and men (research question QoL-1) respectively participants from Austria and the US (QoL-2) differ in their quality of life variables I calculated a two-factorial ANCOVA, where the dependent variables are the QoL items and scales, adjusted to the four covariates EDSS, age, MS duration, and educational status. As can be seen in Table 6.1, no significant differences neither in gender nor in nationality could be identified in the two factorial ANCOVA on the two subscales *QoL mood* (gender: F(1,118)=.86, p=.35; nationality: F(1,118)=2.19, p=.14, gender x nationality: F(1,118)=.29, p=.59) and *QoL social function* (gender: F(1,118)=.08, p=.78, nationality: F(1,118)=1.79, p=.18, gender x nationality: F(1,118)=.57, p=.45). The right part of Table 6.1 shows the means and standard deviation of the scales, high mean values on the subscales describe a low QoL. Concerning the covariate controlled for in these calculations I identified significant effects of the covariate EDSS on the result of the social function scale (F(1,118)=5.58, p=.02).

	p			Women		Men		Austria		US	
	gender	nation	g x n	M	SD	M	SD	M	SD	M	SD
sex life	0.33	0.01	0.27	3.17	0.15	2.94	0.19	3.43	0.18	2.68	0.18
normal life	0.11	0.14	0.18	2.73	0.12	3.04	0.15	3.50	0.14	2.73	0.14

Table 6.2: Results of QoL items on satisfaction with sex life and ability to live a normal life. Covariance analysis (calculated with two-factorial ANCOVA) of gender, nationality, and gender crossed with nationality (g x n) as p-values. The right side of the table shows means and standard deviations for gender and nationality on a scale from 1 to 5, where high values correspond to a satisfying sex life respectively being able to lead a normal life.

Additionally, I calculated a two-factorial ANCOVA with the QoL single items 'I am satisfied with my sex life' and the item 'How far does MS affect your ability to live a normal life?'. As can be seen in Table 6.2, there are significant differences regarding nationality on the item 'satisfaction with sex life' (F(1,118)=7.50, p=.01, M Austria: M=3.43, US M=2.68; see Table 6.2 for details). High mean values on the sexuality item describe a high satisfaction. Austrian participants describe a higher satisfaction in comparison to US participants. No significant differences can be pointed out regarding gender and satisfaction with sexuality (women M=3.37, men M=2.94) as both sexes describe a rather high satisfaction with their sex life. There are no significant differences on the item 'living a normal life with MS'. Here, low mean values describe that MS affects participants are not affected a lot to live a normal life (Austria M=3.5, US M=2.73, women M=2.73, men M=3.04; see Table 6.2 for details). There are no significant effects of the four covariates on the results of the ANCOVA.

For a general overview of QoL of MS patients in the context of mood, social function and sexuality, I constructed the scale 'social-emotional QoL'. As can be seen in Table 6.3, there are no significant differences on this scale regarding gender (disproving QoL-1) and nationality (disproving QoL-2), but statistical tendencies in differences in nationality (F(1,118)=3.76, p=.06; Austria M=2.16, US M=2.42). High mean values on this scale describe a low QoL. Austrian participants describe a higher social-emotional QoL in comparison to US participants. Concerning the covariate control I identified significant effects of the covariate EDSS on the result (F(1,118)=5.22, p=0.02).

		p		**Women**		**Men**		**Austria**		**US**	
	gender	**nation**	**g x n**	**M**	**SD**	**M**	**SD**	**M**	**SD**	**M**	**SD**
S.-E. QoL	0.62	0.06	0.39	2.26	0.08	2.23	0.09	2.16	0.09	2.42	0.09

Table 6.3: Results of the social-emotional QoL scale. Covariance analysis (calculated with two-factorial ANCOVA) of gender, nationality, and gender crossed with nationality (g x n) as p-values. The right side of the table shows means and standard deviations for gender and nationality on a scale from 1 to 5, where high values correspond to a low quality of life.

6.1.2 Perceived Health Status

Table 6.4 shows that the perceived health status correlates positively with social-emotional quality of life and that perceived health also correlates with EDSS.

In this section I evaluate the gender and cultural differences of health perception. I asked participants to rate their health status on a scale from 0 (very bad) to 10 (very good). To evaluate differences in gender (research question QoL-3) and nationality (QoL-4) I calculated a two-factorial ANCOVA while accounting for the covariates.

As can be seen in Table 6.5, there are no significant gender differences on the *perceived health status* scale. The overall mean is 6.29 (SD=0.14), i.e., on average study participants rated their health higher than six. A statistical tendency can be pointed out with regards

	QoL-EDSS	**EDSS-Perceived Health**
Correlation	0.22	-0.29
Significance (2-tailed)	0.02	0.00
df	119	113

Table 6.4: Partial Correlations between the social-emotional QoL and EDSS; and EDSS and Perceived Health, adjusted to the six covariates gender, nationality, MS duration, age, education.

	p			**Women**		**Men**		**Austria**		**US**	
	gender	**nation**	**g x n**	**M**	**SD**	**M**	**SD**	**M**	**SD**	**M**	**SD**
Perceived Health	0.44	0.07	0.28	6.39	0.18	6.17	0.22	5.99	0.22	6.58	0.20

Table 6.5: Perceived Health Results. Covariance analysis (calculated with two-factorial ANCOVA) of gender, nationality, and gender crossed with nationality (g x n) as p-values. The right side of the table shows means and standard deviations for gender and nationality on a scale from 1 to 10, where high values correspond to good health.

to differences between Austrian and US participants (F(1,112)=3.46, p=.07). The mean value for Austrian participants is 5.99 (SD=0.22), for US participants 6.58 (SD=0.20). The covariates EDSS and educational status have a significant effect on the result of the ANCOVA (EDSS: F(1,112)=10.8, p=0.00); educational status: F(1,112)=5.28, p=0.02).

6.1.3 Benefit Finding and Quality of Life

I was interested in finding out whether there are positive correlations between the social-emotional QoL and the two BFiMSS subscales *mindfulness* (QoL-5) and *new opportunities* (QoL-6).

	QoL-Mindfulness	**QoL-New Opportunities**
Correlation	-0.18	-0.21
Significance (2-tailed)	0.04	0.03
df	118	118

Table 6.6: Partial Correlations between the social-emotional QoL and the BFiMSS subscales *mindfulness* and *new opportunities*. Two-factorial ANCOVA, adjusted to the six covariates gender, nationality, MS duration, EDSS, age, education.

As can be seen in Table 6.6 there are significant correlations between the social-emotional QoL and the BFiMSS subscales mindfulness (proving QoL-5) and new opportunities (proving QoL-6). These results show that persons who described a high social-emotional QoL also expressed having found benefits in these subscales since having MS.

To summarize, regarding the research questions in the context of QoL, I found that women and men do not differ regarding their social-emotional QoL, which disproves QoL-1. There is also no such difference between Austrian and US participants, thus also disproving QoL-2. Concerning the self perception of participants' health status I was able to show that there are no gender differences, proving QoL-3, and also no differences between nationalities, proving QoL-4.

Concerning benefit finding, the data shows that persons with a high social-emotional QoL also found benefits on the subscale mindfullness (proving QoL-5) and the subscale new opportunities (proving QoL-6).

6.2 Coping

Regarding strategies for coping with MS, more men than women pointed out denial as a strategy in both countries. More women than men in Austria pointed out ambivalence and resignation as a strategy and more women than men in the US pointed out to cope by *being active*. Concerning strategies for coping with stress it can be summarized that more women than men pointed out to have *no strategies* and *positive stress coping strategies*. More men than women pointed out to *ignore stress*. In Austria more men than women pointed out to have *emotional stress reactions*. More participants in the US than in Austria pointed out *positive stress coping activities*. In both countries *positive stress coping strategies* were pointed out very frequently by women and by men.

In the following section I investigate the validity of the assumptions that there are differences between women and men (CaS-1), and Austria and the US (CaS-2) regarding coping strategies for dealing with MS. Furthermore I am interested in differences of coping strategies for stress between women and men (CaS-3), and Austria and the US (CaS-4).

6.2.1 Coping with MS

I asked participants in the qualitative interviews how they cope with the realization that they are ill and how they cope with stress. The following results include women's and men's responses for each category identified.

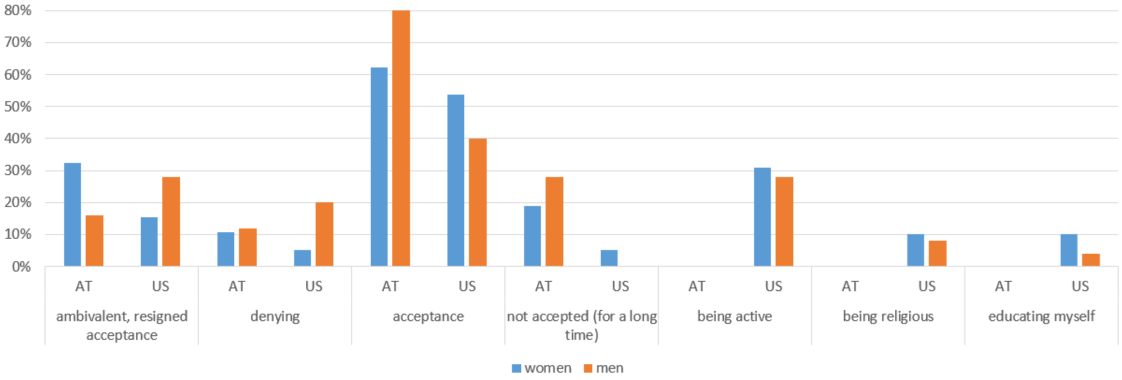

Figure 6.1: Coping with multiple sclerosis split by gender and nationality. Women AT N=37, Men AT N= 25, Women US N=39, Men US N=25.

I identified seven categories of how participants cope with MS, as can be seen in Figure 6.1. The first category called *ambivalent, resigned acceptance* includes statements such as 'Tears, anger, I probably act out on occasion (P laughs), and determination, sometimes I get stubborn, more stubborn than normal, usually I don't slow down as much as I could and push trough when probably sometimes I should step back.' (I10, f, US). In Austria 32% of the women and 16% of the men answered in this category, in the US 15% of the women and 28% of the men.

The category *denying* was pointed out by more men than women (men AT: 12%, men US: 20%; women AT: 11%, women US: 5%). This category includes statements such as 'I don't care, I have identified with it. I don't want to think too much about how I actually feel about it.'[1] (I45, m, AT).

The category *acceptance* was the most common category and was pointed out by 62% of women and 80% of men in Austria and by 54% of women and 40% of men in the US. This category includes statements such as 'I guess the way that I cope is thinking it could be worse. You know its not terminal, I mean I wouldn't say that it's not for the rest of your life, but you can still live a relatively normal life. And I think that's what I mostly do, when I'm down about it, to think it's not as bad as it could be and try to see the positive in it and make it as tolerable as possible.' (I21, f, US).

The category *not accepted (for a long time)* was pointed out by more Austrians than Americans (women AT: 19%, men AT 28%, women US: 5%, men US: 0%). Statements in this category are for example 'It took a long time, much time. I think you have to be open to the fact that you have to change, something happened. You are not dying but the life that you had before is gone. You have to accept before you move on and change in a way that is beneficial for you.' (I58, f, US).

The category *being active* was not pointed out in Austria at all and by 31% of women and 28% of men in the US. This category includes statements such as '(Deep sigh). I do Mantra a lot; I talk to myself a lot. Meditation. Tell myself repeatedly it could be worse, it could always be worse. I drive myself to practice, you know I play the guitar. The MS made that harder, and I fight to get (the ability) back. I have always thrived when somebody was telling me I can't do it. Just to prove him wrong.' (I51, m, US).

The coping strategy *being religious* was pointed out by no Austrian participant and 10% of women and 8% of men in the US. This category includes statements such as 'I have a positive attitude and that is pulling me religiously. I know that there is a god and he is taking care of me, because he says. And that's what keeps me going. Religiously, I have faith in god.' (I06, f, US).

The category *educating myself* was not mentioned in Austria while 10% of women and one man in the US gave answers in this class. It includes statements such as 'Educating myself. I guess I feel like having more control over the situation if I am active in my care, just being conscientious.' (I31, m, US).

6.2.2 Coping with Stress

I asked the question 'How do you cope with stress?' to get an overview of strategies participants used when having to deal with stress. As can be seen in Figure 6.2, I identified eight different categories for coping with stress.

The category *trying to avoid stress* was pointed out by more persons in Austria than in the US (women AT: 17% men AT: 1 person, women US: 1 person, men US: none). Statements of this category are for example 'I avoid stress as much as possible and try to stop it from happening'[2] (I10, w, AT).

The category *no strategies* was pointed out by 28% of women and one man in Austria and by 21% of women and by 16% of men in the US. Statements in this category are for

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[1] Das ist mir eigentlich egal, ich habe mich damit identifiziert. Will nicht viel darüber nachdenken, wie es mir eigentlich damit geht.

[2] Ich meide ihn so gut wies geht und ich lasse ihn nicht aufkommen.

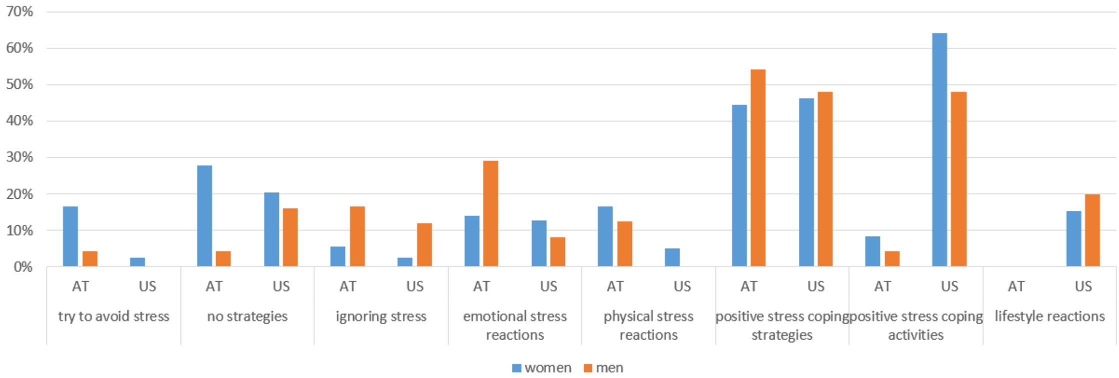

Figure 6.2: Categories for coping with stress split by gender and nationality. Women AT N=36, men AT N= 24; women US N=39; men US N=25.

example ‘I always try to say its gonna be ok, its gonna be ok, but in the back of my mind I’m wondering if it’s really going to be ok. I tend to overthink things, in a sense where I think what could be five years from now, instead of living just for today, for the moment. So I tend to get very overwhelmed with stress.’ (I13, f, US). This category also includes answers such as ‘I don’t cope well with stress’.

The category *ignoring stress* includes anecdotes, such as, ‘I try to relax and ignore it. Whatever stresses me out I try to ignore it.’ (I42, m, US). It was mentioned by more participants in Austria in comparison to the US (women AT: 6%, men AT: 17%, women US: one person, men US: 12%).

Emotional stress reactions was a category that was pointed out by more Austrian than US participants (women AT: 14%, men AT: 29% men, women US: 13%, men US: 8%). Statements of this category are for example ‘Stress is like poison for me. I get nervous, insecure.’[3] (I27, m, AT).

The category *physical stress reactions* was more often mentioned by Austrian than US participants (women AT: 17%, men AT: 13%, women US: 5%, men US: 0). Statements of this category are, for example, ‘I don’t like stress, it makes me not feel very good, I get symptoms—numbness, tingling, I can’t walk right.’ (I52, f, US).

Answers in the category *positive stress coping strategies* were given by 44% of women and 54% of men in Austria and by 46% women and 48% men in the US. This category includes statements such as ‘Just try to think my way through it, visualize my way through certain situations.’ (I50, f, US), ‘Making a plan, having things written down so that I know what I’m doing. I sort of take a step back and write down what’s happening and how to deal with it.’ (I40, f, US), ‘The best way that I can. Honestly, I pretty much stay quiet, stay calm and do my own things. If I wanna go for a walk or take a drive somewhere, I do that. I just try to separate myself from what the problems are. Try not to get overexcited about things, because stuff can always be fixed.’ (I27, m, US), or ‘I don’t let something stress me. I get up on time in the morning, then I have no stress in the morning’[4] (I39,

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[3] Stress ist für mich nix, also das ist eher Gift. Weil da werde ich nervös, da werde ich unsicher.

[4] Ich lass mir einfach keinen Stress mehr machen. Ich stehe rechtzeitig auf, dann habe ich auch keinen Stress, vermeide ich Stress in der Früh.

m, AT).

Positive stress coping activities are more common among participants in the US in comparison to Austrian participants (women AT: 8%, men AT: 1 person, women US: 64%, men US: 48%). This category includes statements such as 'I write a lot, I create on so many levels, I paint, I sculpt, I have friends to talk to. I'm no antisocial man, I have a strong background, that also helps.' (I14, m, US), or 'I try to schedule times with friends for a walk or dinner. I'm in a group of friends reading books and we meet every two months.' (I25, f, US).

The category *lifestyle reactions* was not mentioned in Austria at all and by 15% of women and 20% of men in the US. This category includes statements such as 'Lot of the time the stress is, I just feel like there is too much important work to do. So unfortunately how I cope with that I usually work on Sundays or work six days a week.' (I25, f, US), 'Ahm, ahm, marihuana, I do tend to drink a little bit, I spend money, I eat.' (I12, m, US) or 'Probably I would say if I was really stressed out, I would go to have a drink.' (I54, m, US).

6.3 Personal Circumstances

In this section I take a closer look at different types of personal circumstances of participants. While general differences in personal circumstances are described in Chapter 5, here I evaluate whether there are differences in circumstances in the context of their quality of life by using a correspondence analysis. A correspondence analysis reduces the information and shows particularities of the data. It defines similarities oriented on average values. The average is defined by the cross of the axes, so points close to the center are very similar to the average. Coordinate axes are defined by the attributes. The results of the analysis are shown in Figure 6.3.

In the analysis I included nine variables: *gender*, *EDSS* (binned into high, medium, and low), the *living situation* of participants (in a city, in a municipality, in a village), *age* (20-39, 40-49, 50-57), *family situation* (married, single, divorced, civil union, in a relationship), *educational level* (no completed secondary education, completed secondary education, completed higher education), *monthly net income* (below 550 USD, five intervals between 550 USD and more than 2.300 USD), *QoL mood* (high, medium, low), *QoL social function* (high, medium, low).

Figure 6.3 shows the relationships between all these variables. The axes define the average of the answers, points away from the axes show particularities of the sample in the context of the variables chosen. Points close to each other describe particularities of special personal circumstances. Low EDSS values are associated with negative values on the X axis and high EDSS values with positive values on the X axis.

As can be seen in the Figure 6.3 the two axes F1 and F2 together have an adjusted inertia of 50.93% (F1 30.33%, F2 20.60%). F1 has an eigenvalue of .25, F2 has an eigenvalue of .22. Eigenvalues are used to condense the variance in a correlation matrix. Factors with large eigenvalues have the most variance. I identified five different types of personal circumstances:

- **High income, mild MS:** This living situation type is characterized by the following attributes: being aged 50 to 57, being married, being a woman, having a high income (2,000 USD monthly or more), being highly educated and having a mild form of MS.

- **High QoL:** This type is characterized by living in a village or municipality, and showing high QoL in terms of mood and social function.
- **Low QoL social function:** This type is characterized by having no completed secondary education, a medium QoL mood, and by living in a relationship.
- **Men and MS:** These circumstances are characterized by being a man and living in a civil union respectively by being divorced. This type earns up to 1,700 USD per month, has moderate to severe EDSS scores, a completed secondary education and is 40-49 years old.
- **Low QoL mood:** This type of personal circumstances are characterized by a low QoL mood, a medium QoL social function, having a monthly net income of up to 1,150 USD and by being in a relationship.

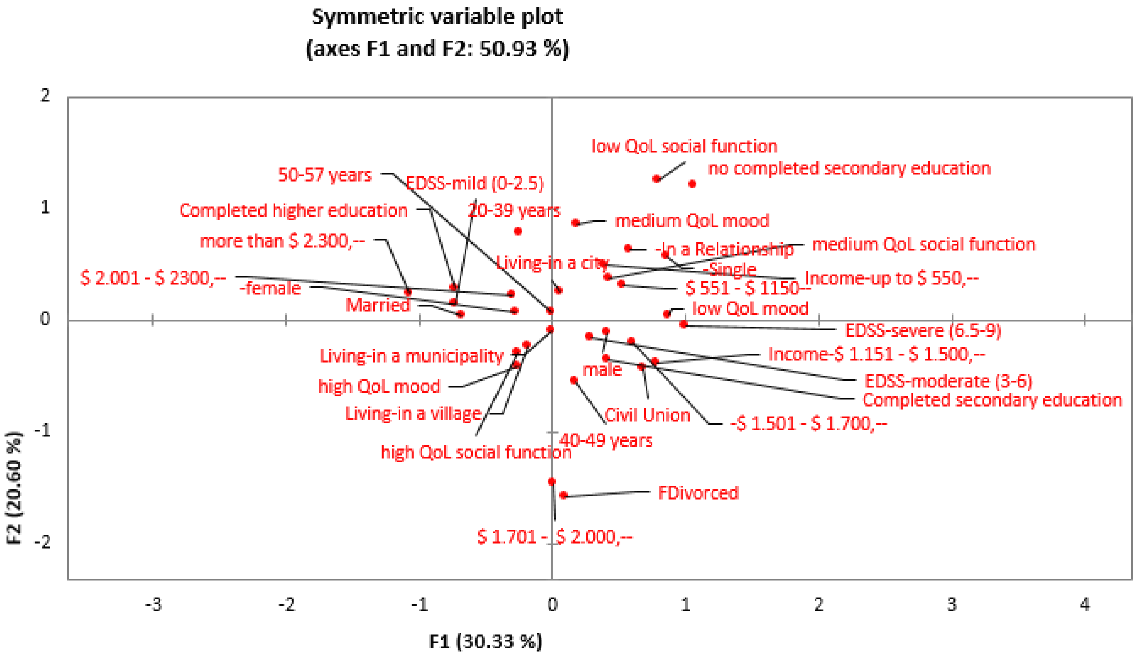

Figure 6.3: Differences in personal circumstances among persons with MS in the context of their quality of life. Points close to each other describe similarities of answer patterns and describe particularities of people which differ from the average values of the answers. The axes describe the average respectively mean answer patterns to the categories. Average answers are not shown, as they build the axes of the correspondence analysis. Points being close to each other are summarized in different living situation types. I identified five types of living situations, characterized by the points which are close to each other: 'high income, mild MS', 'high QoL', 'male and MS', 'low QoL mood', 'low QoL social function'.

6.4 Personality and Mental Health

In this section I evaluate the research question regarding personality and mental health. The assumptions in this context deal with whether women and men (PMH-1) and participants from Austria and the US (PMH-2) differ in their self-esteem. Furthermore I am interested in whether women and men (PMH-3) and participants from Austria and the US (PMH-4) differ in their ability to love and in correlations between feeling a purpose in life and self-esteem (PMH-5). Research question PMH-6 is concerned with correlations between self-esteem and social-emotional QoL, while question PMH-7 deals with correlations between the ability to express love and social-emotional QoL.

I identified that US participants showed a higher self-esteem in comparison to Austrian participants. Additionally I found that men showed lower mean values on the *ability to love* scale compared to women. I also found that persons with a high self-esteem also feel a sense of purpose in their lives and that persons with a high self-esteem also show a high social-emotional QoL. Regarding the ability to express love there is a statistical tendency that persons with a high ability to express love also show a high social-emotional QoL.

6.4.1 Self-Esteem and Ability to Love

Table 6.7 shows the results of the two-factorial ANCOVA relevant for the assumptions regarding self-esteem and ability to express love in the context of gender and nationality (PMH-1 to PMH-4). Women do not differ from men in their self-esteem (disproving PMH-1) Austrians show significantly lower values on the self-esteem scale in comparison to US participants (F(1,118)=4.94, p=.03; Austria M=2.67, US M=2.88), which proves assumption PMH-2. Low mean values on these subscales describe a low self-esteem. There are no significant effects of the four covariates on the results of the self-esteem scale.

Concerning the ability to express love, women show significantly higher values than men (F(1,118)=12,74, p=.00; women M=3.33, men M=3.09). This proves assumption PMH-3. In addition I identified a significant interaction of gender and nationality on the ability to love, shown in Table 6.8 (F(1,118)=4.65, p=.03). I found no national differences in the ability to love (disproving PMH-4). Here, I identified significant effects of the covariates EDSS and MS Duration on the result (EDSS: F(1,118)=5.75, p=.02; MS Duration: F(1,118)=4.12, p=.05).

		p		**Women**		**Men**		**Austria**		**US**	
	gender	**nation**	**g x n**	**M**	**SD**	**M**	**SD**	**M**	**SD**	**M**	**SD**
self esteem	0.14	0.03	0.88	2.84	0.05	2.71	0.07	2.67	0.06	2.88	0.06
ability to love	0.00	0.16	0.03	3.33	0.04	3.09	0.05	3.15	0.05	3.26	0.05

Table 6.7: Self-esteem and ability to love results. Covariance analysis (calculated with two-factorial ANCOVA) of gender, nationality, and gender crossed with nationality (g x n) as p-values. The right side of the table shows means and standard deviations for gender and nationality on a scale from 1 to 5, where high values correspond to high self-esteem respectively ability to love.

		M	SD
Austria	Women	3.20	0.06
	Men	3.11	0.07
US	Women	3.46	0.07
	Men	3.07	0.07

Table 6.8: Interaction of gender and nationality on the *ability to love* scale in persons with MS.

In summary, I was able to show that persons with MS have high values in self-esteem, while Americans have even higher values, validating PMH-2. As there is no gender differences with respect to self-esteem I conclude that assumption PMH-1 is disproven.

PMH-3 is about gender differences in the context of ability to love, which the data supports—women showed higher values in their ability to express love. PMH-4 turned out to be wrong: there are no national differences in the ability to express love.

6.4.2 Purpose in Life and Self-Esteem

In this subsection I evaluate whether perceiving a purpose in life correlates positively with self-esteem (PMH-5). I calculated the partial correlation between the self-esteem scale and the item ‘I feel a sense of purpose in my life’ from the QoL questionnaire while controlling the six covariates nationality, gender, EDSS, MS duration, age and education in the partial correlation. I identified a significant positive correlation between the subjective perception of having a purpose in life and the self-esteem scale (r=.42, p<.01). The results show that persons perceiving a strong purpose in life also show high values on the self-esteem scale, which verifies assumption PMH-5.

6.4.3 Self-Esteem and Quality of Life

To have a closer look at self-esteem in the context of QoL (PMH-6), I correlated the self-esteem scale with the two QoL subscales *mood* and *social function* and with the *social-emotional QoL* scale.

	QoL Mood	**QoL Social Function**	**Social-Emotional QoL**
Correlation	-0.60	-0.43	-0.59
Significance (2-tailed)	0.00	0.00	0.00
df	118	118	118

Table 6.9: Partial correlation of **self-esteem** with three QoL scales *mood*, *social function* and *social-emotional QoL* adjusted to the six covariates nationality, gender, EDSS, age, MS duration, and highest level of education.

As can be seen in Table 6.9 there is a significant correlation between self-esteem and the perceived QoL. The result describes that person with a high QoL also have a high self-esteem (social-emotional QoL: $r = -.59$, $p < .01$; QoL mood: $r = -.60$, $p < .01$; QoL social function: $r = -.43, p < .01$). For the partial correlations the six covariates age, nationality, gender, EDSS, highest level of education, and MS duration were controlled.

In summary, we can conclude that persons with a high self-esteem also have a high QoL, which confirms assumption PMH-6.

6.4.4 Ability to Love and Quality of Life

	QoL Mood	**QoL Social Function**	**Social-Emotional QoL**
Correlation	-0.18	-0.11	-0.16
Significance (2-tailed)	0.05	0.23	0.08
df	118	118	118

Table 6.10: Partial correlation of **ability to love** with the three QoL scales mood, social function, and social-emotional QoL adjusted for the six covariates nationality, gender, EDSS, age, MS duration, and education.

I assume that persons with a high QoL also have a high ability to express love (PMH-7). As shown in Table 6.10 the QoL scales correlate positively, but not significantly, with *ability to love*. QoL mood shows a statistical tendency in correlation with the *ability to love* scale ($r = . - 18, p = .05$), as does the *social-emotional QoL* scale ($r = -.16, p = .08$). The *social function* scale ($r = -.11, p = .23$) is not strongly related to *ability to love*. It can be concluded that persons with a high QoL often point out a strong ability to express love as well, although these results only show statistical tendencies. Thus I could not prove assumption PMH-7.

6.5 Benefit Finding in Multiple Sclerosis

In the following I present in detail the statistical data analysis for testing the assumption regarding perceived positive changes in life since being diagnosed MS (BFiMS-1). When there are such benefits, I also discuss which aspects of their life participants found these benefits in. The data shows that participants found benefits in MS, especially regarding compassion, mindfulness, life style gains, family relations growth and personal growth. I did not identify significant differences in gender or nationality related to benefit finding.

6.5.1 Overall Benefit Finding

I found that women as well as men in Austria and the US describe benefits since being diagnosed MS, as can be seen in the right part of Table 6.11. Mean values higher than two mean that on average benefits in these scales have been perceived even more than just ‘a little bit’ (between ‘a little bit’ and ‘a great deal’). The (adjusted) mean value over all 41 items used for the calculation of the subscales is 2.07 (SD=0.33), showing that positive changes since being diagnosed with MS have been noticed by participants. Adjusted mean values higher than two were found for the subscales compassion (M=2.19, SD=.05), mindfulness (M=2.16, SD=0.04), life style gains (M= 2.37, SD=0.05)), family relations growth (M=2.09, SD=0.04) and personal growth (M= 2.03, SD=0.04).

		p		**Women**		**Men**		**Austria**		**US**	
	gender	**nation**	**g x n**	**M**	**SD**	**M**	**SD**	**M**	**SD**	**M**	**SD**
Compassion	0.78	0.56	0.00	2.18	0.06	2.21	0.07	2.23	0.07	2.16	0.07
Spiritual Growth	0.58	0.19	0.30	1.73	0.07	1.67	0.09	1.62	0.09	1.79	0.09
Mindfulness	0.15	0.75	0.17	2.22	0.05	2.10	0.06	2.18	0.06	2.15	0.06
Opportunities	0.74	0.38	0.79	1.87	0.06	1.84	0.07	1.90	0.07	1.81	0.07
Lifestyle Gains	0.39	0.44	0.79	2.40	0.04	2.34	0.05	2.34	0.05	2.40	0.05
Family Relations	0.76	0.34	0.09	2.10	0.05	2.08	0.06	2.14	0.06	2.04	0.06
Personal Growth	0.75	0.10	0.73	2.04	0.06	2.01	0.07	1.94	0.07	2.11	0.07
Total BFIMSS	0.58	0.85	0.20	2.10	0.04	2.06	0.05	2.07	0.05	2.08	0.05

Table 6.11: Differences in Gender and Nationality on the seven BFIMSS subscales. Covariance analysis (calculated with two-factorial ANCOVA) of gender, nationality, and gender crossed with nationality (g x n) as p-values. The right side of the table shows means and standard deviations for gender and nationality on a scale from 1 to 3, where high values correspond to high benefits.

6.5.2 Benefit Finding, Gender and Nationality

I calculated a two-factorial ANCOVA with the seven subscales of the BFIMSS and looked at differences in gender and nationality, while controlling the four covariates (EDSS, MS duration, age, education). I identified no significant differences in gender or nationality concerning the BFIMSS subscales, as can be seen in Table 6.11, which also shows the mean values of the subscales for gender and nationalities.

		M	SD
Austria	Women	2.07	0.09
	Men	2.38	0.11
US	Women	2.29	0.10
	Men	2.03	0.10

Table 6.12: Interaction gender x nationality on the BFIMSS subscale 'compassion'.

There is a significant interaction gender x nationality on the subscale *compassion* (F(1,118)=8.48, p=.00). In Table 6.12 I show the mean values of the interaction on the *compassion* scale with gender and nationality. In Austria women show lower mean values on the *compassion* subscale in comparison to Austrian men (women M=2.07, men M=2.38), while in the US women show higher mean values in comparison to men (women M=2.29, men M=2.03).

For the following scales there were significant effects of the covariates age, EDSS and education on the result:

- Compassion: Education (F(1,118)=6.23, p=.01).
- Spiritual Growth: Education (F(1,118)=7.55, p=.00).
- Mindfulness: Education (F(1,118)=4.7, p=.03) and EDSS (F(1,118)=8.02, p=.01).
- New Opportunities: EDSS (F(1,118)=5.46, p=.02).
- Lifestyle Gains: EDSS (F(1,118)=7.64, p=.01).
- Family Relations Growth: Education (F(1,118)=5.94, p=.02).
- Personal Growth: Age (F1,118)=4.51, p=.04).

We can conclude that participants identified positive changes in different fields of their life, independent of gender and nationality, which proves assumption BFIMS-1.

6.6 Social Support

In the following I address the role of social support when having MS and want to know whether there is a difference in gender (SoSu-1) and nationality (SoSu-2) concerning social support. Additionally I am interested in whether there are correlations between social support and the TPF subscales *self-esteem* (SoSu-3) and *ability to love* (SoSu-4). Furthermore I am interested in whether there are correlations between the *social support* scale and the BFIMSS subscales *mindfulness* (SoSu-5), and *family relations growth* (SoSu-6).

I identified no significant differences in gender and nationality concerning *social support*. There is evidence that affected receiving social support as well pointed out having found benefits on the BFIMSS subscale *family relations growth* since having MS. Furthermore I found that persons receiving social support showed a high self-esteem and high values in the ability to express love.

6.6.1 Social Support, Gender and Nationality

To test whether women and men respectively Austrian and US participants differ in their social support, I calculated an univariate two factorial ANCOVA (independent factors: gender, nationality) with the *social support* scale.

As can be seen in Table 6.13 there are no significant differences between gender (F(1,118)=0.46, p=0.50) and nationality (F1,118)=0.05, p=0.83) on the *social support* scale. For the ANCOVA I controlled the four covariates EDSS, MS duration, age, and education.

In summary, I was able to show that there is no gender or cultural difference regarding social support, thus proving assumptions SoSu-1 (gender) and SoSu-2 (nationality).

	p			Women		Men		Austria		US	
	gender	**nation**	**g x n**	**M**	**SD**	**M**	**SD**	**M**	**SD**	**M**	**SD**
Social Support	0.50	0.83	0.15	3.82	0.12	3.72	0.15	3.77	0.14	3.81	0.14

Table 6.13: Differences in gender and nationality on the *social support* scale. Covariance analysis (calculated with two-factorial ANCOVA) of gender, nationality, and gender crossed with nationality (g x n) as p-values. The right side of the table shows means and standard deviations for gender and nationality on a scale from 1 to 5, where high values correspond to a high degree of social support.

6.6.2 Social Support, Self-Esteem and Ability to Love

As can be seen in Table 6.14 both TPF subscales *self-esteem* and *ability to love* correlate positively with the *social support* scale, which proves assumptions SoSu-3 (correlation social support with self-esteem) and SoSu-4 (correlation *social support* with *ability to love*).

	Self-Esteem	**Ability to Love**
Correlation	0.32	0.20
Significance (2-tailed)	0.00	0.03
df	118	118

Table 6.14: Partial correlations of the **social support scale** with the TPF subscales *self-esteem* and *ability to love*, adjusted to the six covariates EDSS, MS-duration, age, highest level of education, gender and nationality.

6.6.3 Social Support and Benefit Finding in Multiple Sclerosis

As can be seen in Table 6.15 there is a significant positive correlation of the social support scale and the BFIMSS subscale *family relations growth* (proving SoSu-6). Additionally there is a statistical tendency in the correlation between mindfulness and social support. Hence I could not verify SoSu-5. I adjusted the partial correlations to the six covariates EDSS, MS duration, age and highest level of education, gender and nationality.

In summary, the data shows a positive correlation between social support and family relations growth, proving assumption SoSu-6, while the evidence for SoSu-5—a relationship between social support and mindfulness—is not significant.

	Mindfulness	Family Relations Growth
Correlation	0.18	0.36
Significance (2-tailed)	0.05	0.00
df	118	118

Table 6.15: Partial correlations of the **social support scale** with the BFIMSS subscale *mindfulness* and *family relations growth* adjusted to the six covariates gender, nationality, EDSS, MS-duration, age, highest level of education.

6.7 Interview Results

By analyzing the interviews I want to elicit aspects of living with MS that are not covered by the quantitative questionnaire. Asking open questions gave me insights into how participants experienced their daily life with MS, their wishes and their burdens. I was interested in whether affected women and men differ in their expectations in the medical context, their health literacy and their experiences in living with MS (LiMS-1). In addition I am interested in whether affected from Austria and the US differ in their expectations in the medical context, their health literacy and their experiences in living with MS (LiMS-2). In the following I present results of the interviews and illustrate the individual categories with quotations. In summary, I identified the following results in the qualitative interview:

Wishes to be different Women wish to 'be more active' and 'more patient' in comparison to men. Men on the other hand pointed out more often than women the wish to be in 'better health/have no MS' and the wish to be 'more social'.

Perception of own (in)dependence The majority of women rated themselves as independent. Men in Austria also rated themselves as being independent, US men, though, least frequently characterized themselves as independent. A higher percentage of Austrians rated themselves as being dependent in comparison to US participants. More US participants rated themselves as somewhere in-between in comparison to Austrian participants.

Support services used 'Medication' as well as 'physical therapy' where mentioned frequently as support services used in both countries. In the US 'doctors/hospital' was pointed out most frequently, while 'in-patient physical rehabilitation' was pointed out most often in Austria.

Life events before MS 'Negative family/social experience' and 'death of a loved person' were pointed out frequently in both countries. 'Positive family and social experiences' where most frequently mentioned by US women.

Negative experiences with medical personnel More than a third of the participants reported negative experience with medical personnel. More women than men reported such experiences.

Caregiver Coordination 80% of participants described the coordination of their medical caregivers as good, while 15% pointed out that the coordination is bad, and 5% said that they do not know about the coordination of their caregivers. These results are consistent between countries.

Information about MS The major sources of information about MS were pointed out to be ‘books, reading, own research’, the main source in Austria, and ‘Internet/Media’, the main source in the US. Further categories identified were ‘MS organizations’, which were more often mention in the US.

Wishes for services not currently offered Wishes often mentioned were having more ‘therapies and educational support’, getting more ‘information’, as well as wishes addressing the ‘medical context’ and finding a cure for MS.

Personal therapy cooperation The percentage of the perception of the ‘importance of the own therapy cooperation’ is very high in both countries, although men were more sceptical about it than women.

MS education I found that 31% in Austria and 44% in the US would be interested in courses dealing with topics around MS.

Proper care Beside ‘getting adequate medication’ many supporting areas were pointed out, especially support in organizing medical appointments, support from medical personnel and getting more information. The wish for a cure was pointed out very often as important criterion for proper care.

Subjective explanations for MS Stress, prior illnesses, vaccinations, lifestyle, and destiny were pointed out as personal explanations for MS.

Changes in life since MS Experiencing boundaries was the category most often mentioned followed by physical changes, with regards to changes since the MS diagnosis.

Significant experiences with MS Beside significant experiences in the social environment, physical changes were described most often as significant experience.

Hobbies Hobbies were expressed in the five fields exercise, social activities, solitary activities, volunteer work, and spiritual activities.

Help when at wits’ end Most often partners and spouses were pointed out as help when being at the wits’ end, followed by friends and parents.

Given these results I can conclude that the assumptions LiMS-1 and LiMS-2—that women and men, as well as Austrians and Americans differ in their expectations in the medical context, their health literacy and their experiences in living with MS.

In the following I present the data in detail. The questions are classified into the seven categories **self perception**, **living MS**, **health literacy**, **subjective perception of the illness**, **questions related to QoL**, **hobbies** and **social support**.

6.7.1 Self Perception

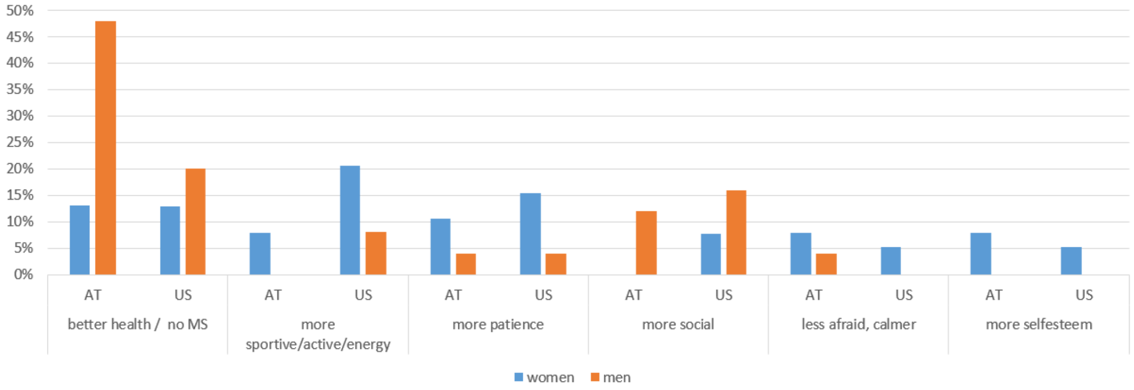

Figure 6.4: Wishes to be different split by gender and nationality. Men US N=25, men AT N= 25, women US N=39, women AT N=38.

I asked participants in which aspects they would wish to be different. As can be seen in Figure 6.4 the most common desired change is *improved health*. In particular, men in Austria frequently pointed this out, but also one fifth of US males expressed this (AT: 48%, US: 20%), while women, in comparison, mention this more infrequently (13% in each country). Example statements in this category are ‘I wish my health was better for myself and everybody close to me.’ (I59, m, US), or ‘I wish that this disease wasn’t taking its course and I could do more with my son and I could go back to my life prior to MS.’ (I13, f, US).

Furthermore in both nations more men in comparison to women pointed out the wish to *be more social* (men AT: 12%, men US: 16%, women: AT 0%, women US: 8%). The category includes statements such as ‘I wish I was more attentive to other people.’ (I12, m, US), or the wish to be ‘more empathetic, more compassionate’ (I52, f, US).

In contrast, more women than men pointed out the wish to *be more active*, *less afraid, calmer* and having *more self-esteem*. The latter category includes statements such as ‘Mhm, I guess more confident with myself.’ (I21, f, US), ‘More confident, better self-esteem.’ (I21, f, US), or ‘I would like to give myself more worth. That’s sometimes difficult.’[5] (I43, f, AT).

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[5] Würde gern mehr von mir selbst halten, das ist oft schwierig.

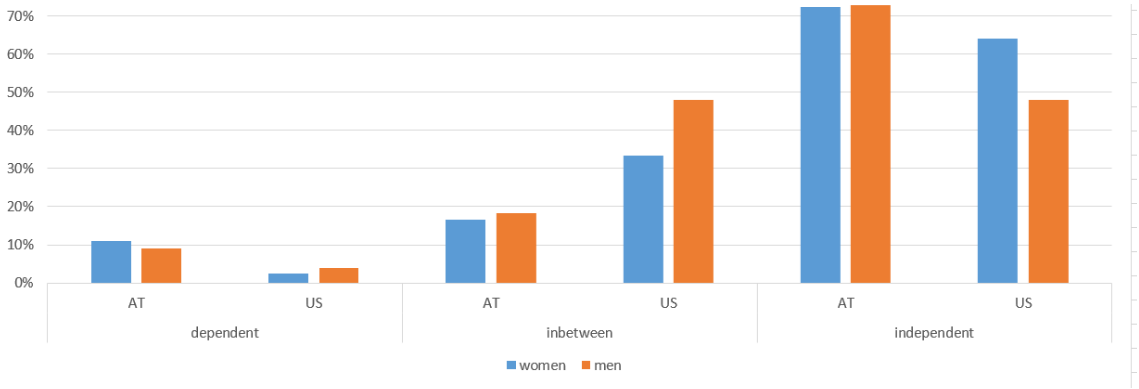

Figure 6.5: How participants rate themselves with the illness split by gender and nationality. Women AT N=36, men AT N= 22, women US N=39, men US N=25.

6.7.2 Living Multiple Sclerosis

I asked study participants how they rate their independence with respect to the disease, trying to elicit whether they perceive themselves as independent, having to rely on others or somewhere in-between. As can be seen in Figure 6.5, the majority of women rated themselves as *independent* (women AT: 72%, women US: 64%). Men in Austria also rated themselves as being independent, US men, though, least frequently characterized themselves as independent (men AT: 73%, men US: 48%). A higher percentage of Austrians rated themselves as being *dependent* in comparison to US participants (women AT: 11%, men AT: 9%, women US: 3%, men US: 4%). More US participants rated themselves as somewhere in-between in comparison to Austrians (men AT: 18%, men US: 48%, women AT: 17%, women US: 33%).

The category *independent* includes anecdotes such as ‘Mostly independent. You know. I have had two major sorts of flare-ups of symptoms. I was more dependent when this was happening, but otherwise largely independent.’ (I17, m, US). The category *in-between* consists of answers such as ‘I would say I’m in-between. Certain things I’m sort of independent about, but I don’t drive a car. If I can get there myself by public transport, I try to be as independent as I can. I would say in the middle.’ (I21, f, US). In the category *dependent* answers such as ‘I have to rely on others a great deal. More than I would have chosen to.’ (I66, m, US) were given.

6.7.3 Life Events before Multiple Sclerosis

By asking the question ‘Which touching life events did you experience before the illness—positive as well as negative ones?’ I wanted to get an impression of the quality of life and burdens of participants before MS.

I identified six categories of major life events, as can be seen in Figure 6.6. The category *negative family/social experience* includes statements such as ‘My mother kicked me out.’ (I05, m, US) or ‘I was in a relationship which didn’t work out. I mean, if I were diagnosed with my MS five years before I was, my relationship would have worked. I think a lot of the problems I had [were] because of my symptoms of MS, I later realized. But then it

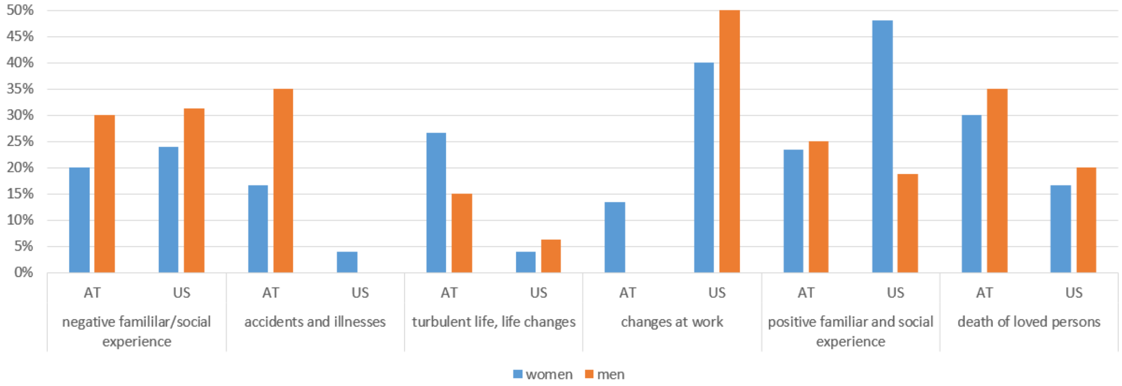

Figure 6.6: Touching life events experienced before being diagnosed with MS split by gender and nationality. Women AT N=30, men AT N=20, women US N=25, men US N=16.

was too late.' (I31, m, US) or 'Problems with my brother, who is, after his drug problems, in an asylum now.'[6] (I30, f, AT).

The category *accidents and illnesses* include statements such as '[I had] a bad car accident.' (I22, f, US) or 'When I was eleven I had a bad bike accident with fracture of the scull base and humeral fracture.'[7] (I10, w, AT).

The category *turbulent life, life changes* includes all answers describing a turbulent life, respectively having made important life changes before the MS, such as life changes through marriage and moving to another town because of this, or traveling abroad for a long time.

The category *changes at work* includes 'starting to work after college' or 'being very successful at work'. The category *positive family and social experience* include descriptions such as 'getting married' or 'the birth of our children'. The last category *death of loved persons* include descriptions of losing loved persons, especially family members.

Women most often answered in the category *positive family and social experience*, followed by the category *changes at work*. Men, in contrast, most often answered in the categories *negative family and social experience* and *losing a loved person*. As can be seen in Figure 6.6, in Austria 23% of women and 25% of men answered in the category *positive family and social experience*, while this number is higher for US women (48%) but lower for US men (19%). *Negative family experience* were pointed out more often by men than women (men AT: 30%, men US: 31%, women AT: 20%, women US: 24%). Statements in the category *death of loved persons* were expressed by 30% of Austrian women and 35% of Austrian men in comparison to 17% of US women and 20% of US men.

Furthermore more Austrian participants answered in the category *accidents and illnesses* (women AT: 17%, men AT: 35%, women US: 4%, men US: 0%). *Turbulent life events* were expressed by more Austrian women than US women (women AT: 27%, men AT: 15%, women US: 4%, men US: 6%). The category *changes at work* was mentioned

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[6] Und dann noch Probleme mit meinem Bruder, der nach Drogenprobleme jetzt [schon lange] in einem Asyl ist. Das war sicher auch ganz einschneidend.

[7] Mit elf hatte ich einen Radunfall mit Schädelbasisbruch und offenem Oberarmbruch.

more often by American participants (women US: 40%, men US: 50%, women AT: 13%, men AT: 0%).

6.7.4 Health System

6.7.4.1 Support Services Used

By asking the question 'Which support services of the health-care system do you use?' I wanted to find out more about health literacy of affected and which support services they use.

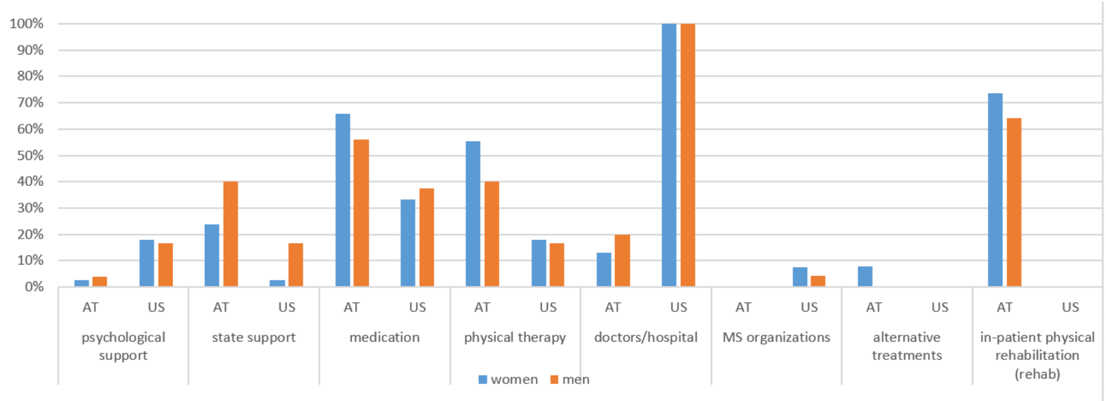

Figure 6.7: Support services used split by gender and nationality. Women AT N=38, men AT N= 25, women US N=39, men US N=24.

As can be seen in Figure 6.7 I identified eight categories of support services. The category *psychological support* includes counseling and psychological support by psychologists and social workers. This category was mentioned by 3% of women and 4% of men in Austria, compared to 18% of women and 17% of men in the US. Answers given in this category are for example 'I do go to a therapist to deal with the stressors' (I22, f, US).

The category *state support* includes answers such as 'I use the rides that come and pick me up to my appointments with the doctors' (I28, m, US) or 'financial state support for my car, car sticker for annual toll and tax reduction for my car.'[8] (I13, m, AT). 24% of women and 40% of men in Austria, and 3% of women and 17% of men in the US answered in this category.

Answers belonging to the category *medication* were given by 66% of women and 56% of men in Austria. In the US 33% of women and 38% of men answered in this category. The category *physical therapy* was mentioned by 55% of women and 40% of men in Austria, while only 18% of women and 17% of men in the US replied in this category. Answers in the category *doctors/hospital* were mentioned by 13% of women and 20% of men in Austria. In the US all women and men answered in this category.

None of the Austrian participants answered in the category *MS organizations*, while it was pointed out by 8% of women and 4% of men in the US. Answers in the category *alternative treatments* were given by 8% of women and no men in Austria, and by no

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[8] Vom Bundessozialamt die Autobahnvignette und die Steuerbefreiung beim Auto und die NoVA

participants in the US. *In-patient physical rehabilitation (rehab)* was only mentioned by Austrians (74% of women and 64% of men).

To sum it up, *medication* was pointed out frequently as a support service used across genders and nations. *Doctors/hospital* was mentioned especially in the US, while *physical therapy* is more prevalent in Austria than the US. While the prevalence of *rehabilitation* in the Austrian leg of the study is likely overstating the general use of it in Austria, it is striking that it was never mentioned in the US. The high prevalence of rehabilitation in Austria is likely not representative as the study was conducted in a rehabilitation center.

6.7.4.2 Negative Experiences with Medical Personnel

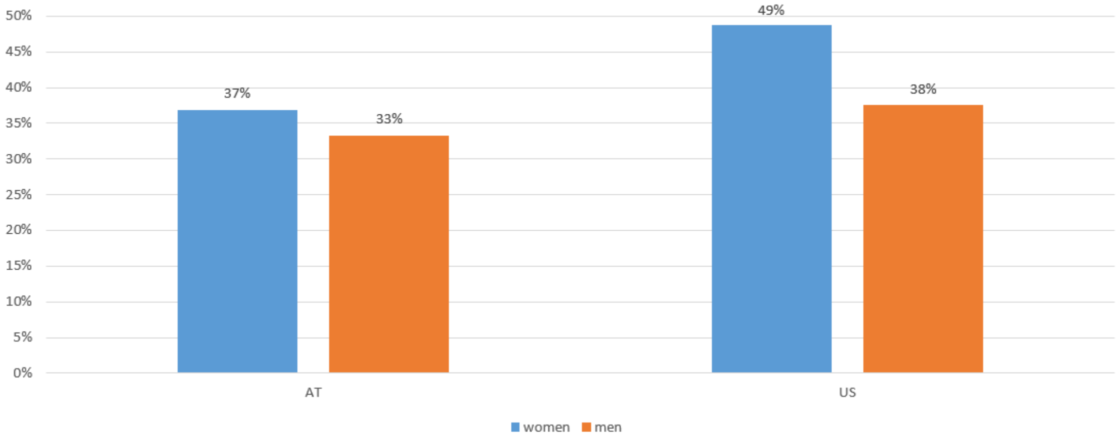

Figure 6.8: Negative experiences with medical personnel split by gender and nationality. Women AT N=38, men AT N=24, women US N=39, men US N=24.

As can be seen in Figure 6.8 more than a third of participants reported negative experience with medical personnel. In Austria 37% of women and 33% of men reported negative experience with medical personnel. In the US 49% of women and 38% of men reported such experiences.

Negative experiences with doctors or nurses include a lack of trust or the feeling of being misunderstood. Also, problems with scheduling doctor's appointments were mentioned. The following quotes illustrate these points: 'Yes, when I first had my relapse respectively lapse, my first doctor, I went to the hospital, I did not have a great deal of trust in him. I did feel he was more interested in selling me medication from the large pharmaceutical companies than hearing my story and working with me. He was also younger than me and I found that a little off-putting. I didn't like him, I didn't like his manner.' (I12, m, US). 'Once. When I received the diagnosis they talked to me only in passing. This was the worst experience in the context of this illness I had.'[9] (I11, m, AT). 'Yes, with my primary care doctor. I don't like him. They want you to go and see them, but I have no way to get there. So they get aggravated that I'm not coming in when they want me in.

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[9] Ja, einmal. [Als] sie mir die Diagnose gegeben haben, das ist mir zwischen Tür und Angel gesagt worden, das war sicher das Negativste bei der Krankheit, was ich je gehabt habe.

They expect me to rearrange others people schedule, but they can't rearrange their own to make it easier for me.' (I48, m, US).

6.7.4.3 Caregiver Coordination

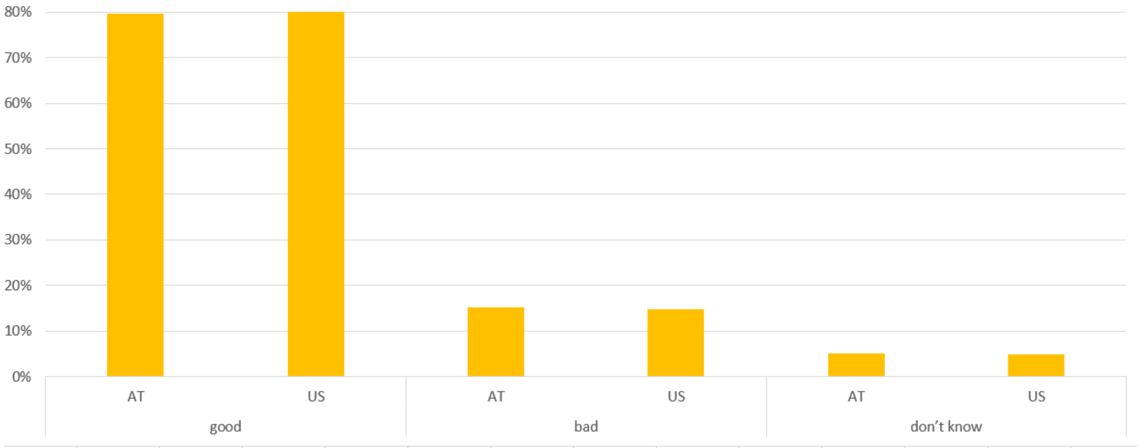

Figure 6.9: Evaluation of the coordination of medical caregivers of affected split by nationality. Austria N=59, US N=61.

I asked 'How well are your caregivers organized/coordinated with each other?' to find out how well doctors and other medical personnel communicate and cooperate with each other. I addressed mainly the communication between the primary care physician (PCP) and the neurologist/MS doctor. As can be seen in Figure 6.9, 80% of participants in Austria as well as the US described the coordination of their medical caregivers as good. This category includes statements such as 'Very well, they both know what each other has ordered and what medications I'm using.' (I30, m, US).

In both countries 15% pointed out that the coordination is bad. Answers in this category are, for example, 'I do not think that they are coordinated. I think they don't talk' (I04, f, US). 5% in both countries said that they do not know about the coordination of their caregivers. Answers in this category are for example 'I'm not really sure of how coordinated they are' (I44, f, US).

6.7.4.4 Information Sources

I asked affected 'How did you get your information, how did you obtain your knowledge about MS?' I identified six categories, as can be seen in Figure 6.10. The category *experience, living MS* includes statements such as 'Really where my knowledge comes from is my experiences. From not being able to lift things, from not being able to feel things, from not being able to walk, to being able to get my strength back to walk and do what I do on a daily basis.' (I27, m, US). The category *talking to other affected* includes statements such as 'Talking to other affected here in the rehabilitation clinic.'[10] (I20, m, AT). The

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[10] Gespräche mit anderen Patienten auf der Reha.

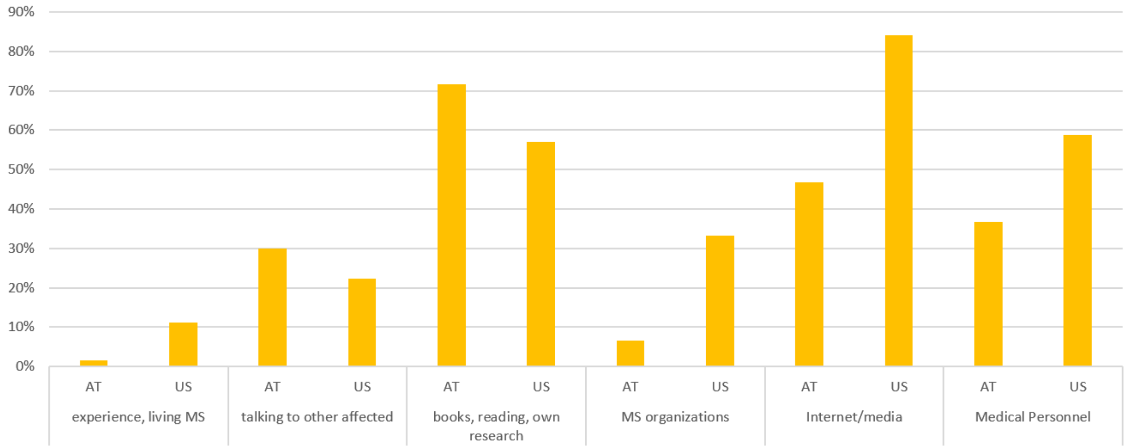

Figure 6.10: Information sources for MS patients split by nationality. Austria N=60, US N=63.

major sources of information about MS were pointed out to be 'books, reading, own research' (72% in Austria, 57% in the US), and *Internet/Media*, which was the main source in the US (84% in the US compared to 47% in Austria). *MS organizations* (AT 7%, US 33%), *medical personnel* (AT 37%, US 59%), as well as *experience, living MS* (AT 2%, US 11%) were more often mentioned in the US than in Austria. More Austrian participants answered in the category *talking to other affected* (AT 30%, US 22%).

6.7.4.5 Wishes for Services Not Currently Offered

As can be seen in Figure 6.11 I identified seven categories of wishes affected pointed out. The first categories deal with support in different areas. *Therapies and education support* describes support through different therapies or educational offers. In Austria 27% women and 39% men answered in this category, while in the US 11% women and 14% men responded similarly. Statements in this category include 'A class that explains very technical aspects of MS. I don't know how I should be feeling about my lesions. Something like that.' (I12, m, US), or 'Horse riding therapy. And an MS group in a mountain cabin, where it is cool, that would be great. With possibilities for affected to get there, even though they don't see well or don't drive anymore ... that these persons don't have to beg others at home to drive them.'[11] (I34, w, AT).

The category *social support and mobility* was mentioned by 18% of women and 6% of men in Austria, while it was mentioned by 7% of women and 14% of men in the US. It includes statements such as 'A personal coordinator. There is so much to coordinate with care and life and stuff. There are just so [many] things I don't want to think about.' (I64, f, US) or 'The type of transportation I need to get to places and the way home. They have types of transportation but they are not helping me when it comes to get up and

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[11] Reittherapie. MS-Gruppe auf einer Almhütte, wo es schön kühl ist. Also so eine Gruppe wäre super. Wo auch Leute hinkönnen, die nicht gut sehen und nicht mehr Autofahren können und man daheim nicht immer betteln muss, dass jemand mit einem fährt.

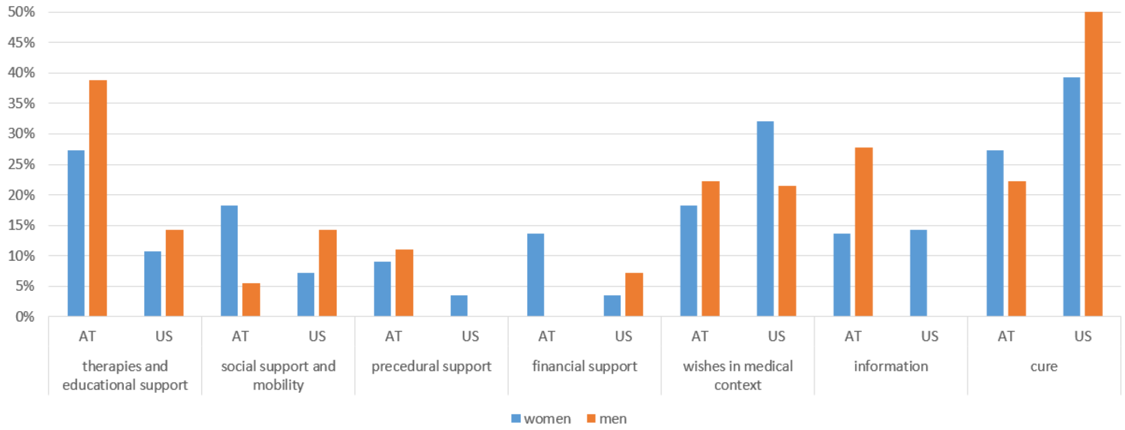

Figure 6.11: Wishes of participants split by gender and nationality. Women AT N=22, men AT N=18, women US N=28, men US N=14.

down stairs.' (I48, m, US).

The category *procedural support* was mentioned by 9% of women and 11% of men in Austria, while only 4% of women and no man in the US responded in this category. It includes statements such as 'Because you have to apply for and document every medication and other support several times. If this would be simplified [that would help].'[12]

The category *financial support* was mentioned by 14% of women and by no man in Austria, and by 4% of women and and 7% of men in the US.

18% of women and 22% of men in Austria, 32% of women and 21% of men in the US responded in the category *wishes in medical context*. This includes statements such as 'I don't believe that the national MS society is putting enough money in research for finding a cure. They are putting their money into pharmaceutical companies, their advertising, the higher-ups in their own salaries and such. I think that between all that money that gets raised between bikes and walks and runs to me it is ludicrous. They have all this money and they are constantly calling your house, looking [for] money to donate. It just doesn't seem the data isn't there, I just don't believe they are pushing as hard as they can.' (I13, f, US), or 'A doctor that covers everything. [Laughing loud]. This is my dream, a doctor that sees me as a whole and accompanies me on my way.'[13] (I28, f, AT).

Answers in the category *information* were given by 14% of women and 28% of men in Austria and by 14% of women and no man in the US. This category includes statements such as 'I wish my doctors talked more about my prognosis and my future, the likelihood that I end up in certain categories. I would rather hear an anecdote than "we do not know". That's frustrating.' (I43, f, US).

The category *cure* describes the wish of patients to be cured, and was pointed out by 27% women and 22% men in Austria, by 39% women and 50% men in the US. This category includes statements such as 'A cure, back to normal' (I33, f, US).

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[12] Weil man muß ja um jedes Medikament und jedes Behelf doppelt und dreifach Einreichen und Dokumentieren. Wenn man das etwas vereinfachen würde [waere das hilfreich].

[13] Ein mal einen Arzt, der alles übernimmt (Anm.: P. Lacht laut). Das ist mein Traumbild, das [ein] Arzt mich als Gesamtheit sieht und wir uns gemeinsam auf den Weg machen.

In summary, wishes for a *cure* where most frequent, followed by *wishes in the medical context* and *support in therapies and education.*

6.7.4.6 Personal Therapy Contribution

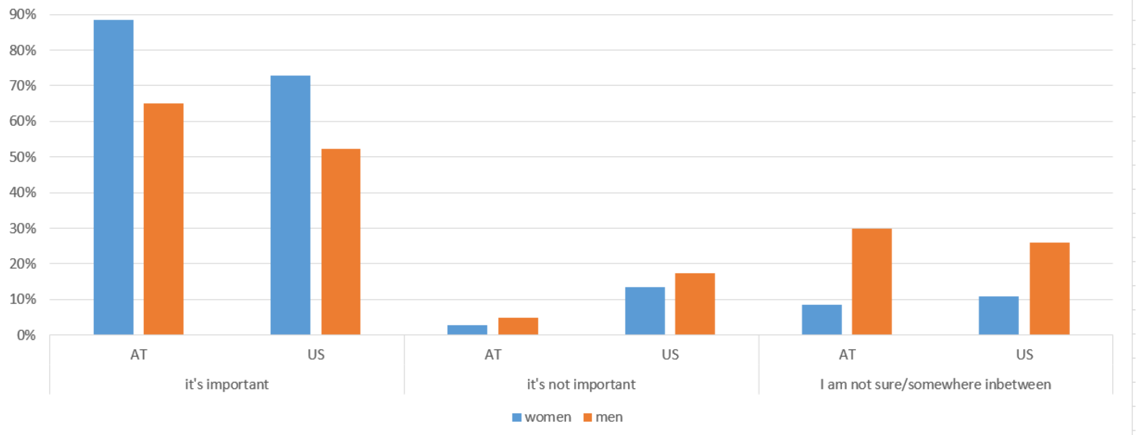

Figure 6.12: The perceived role of personal therapy contribution split by gender and nationality. Women AT N=35, men AT N=20, women US N=37, men US N=23.

I asked participants for their perception of the role of their therapy contribution on their disease progression. The question was: 'What do you think, how much does your cooperation concerning your therapy influence your disease progression? In your opinion, does the coordination of your personal therapy contribute to the progression of your illness?'

As can be seen in Figure 6.12 the majority of persons asked state that therapy contribution is very important (women AT: 89%, men AT: 65%, women US: 73%, men US: 52%). Statements in this category include 'I think, obviously, taking the medication, that thing helps a lot. There is a lot I wish I could do better, cook and eat a bit better, walk regularly, exercise regularly and I really strongly believe that this would have effects on my overall physical well-being and health and that it's a thing that I strive to get to it.' (I25, f, US).

The importance of personal therapy contribution was negated by less than 20% of people asked, with even lower numbers in Austria (women AT: 3%, men AT: 5%, women US: 14%, men US: 17%). This category includes statements such as 'I don't think of anything much influences my disease progression. There aren't any approved or unapproved therapies that have shown effects on [disease] progression. A number of medication affects the inflammatory components of the illness, others reduces the number of exacerbations but there is nothing that actually indicates that this affects long term progression. Lifestyle or diet—nothing has been approved.' (I16, m, US).

The category *not sure, a little bit* was pointed out by 9% of women and 30% of men in Austria and by 11% of women and 26% of men in the US. This category includes statements such as 'Ah, I'm not sure. It's a large questionmark in my mind. I often joke [about] the two puppets Earni and Bert in Sesame street. Bert comes home and Earni has

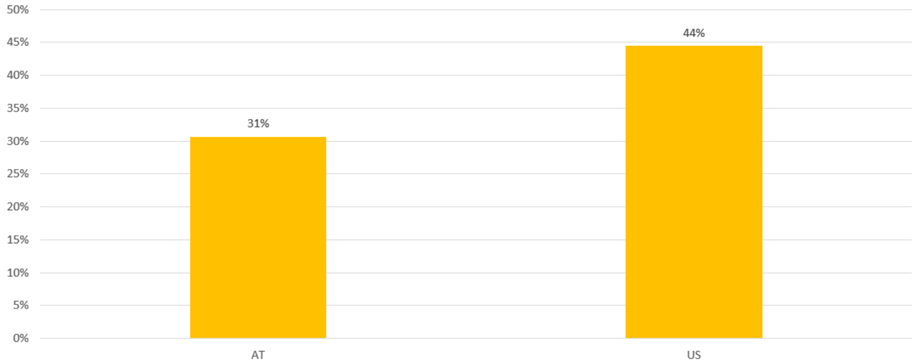

Figure 6.13: Interest in education related to MS split by nationality (Austria N=62, US N=54).

a banana sticking in his ear and Bert asks “So why do you have a Banana in your ear?” And Earni answers “It keeps the alligators away from Sesame street”. And he answers: “There are no alligators in Sesame street.” And Earni says “You see, it is working.” And that is [how it is] for me with MS. You may not have another relapse in your life, you may have one in 5 years, so take your drugs just in case. And when I feel better, maybe it’s my drugs, maybe it’s the banana in my ear. So I don’t know, I kind of enjoy the fact that it’s unclear.’ (I12, m, US).

6.7.4.7 Interest in Education Related to Multiple Sclerosis

As can be seen in Figure 6.13, 31% of Austrian participants pointed out to be interested in educational courses in the context of MS, while the rate was at 44% in the US. Statements in this category are for example ‘Yes, I would like to. To see what’s going on and what’s getting better or worse. To see if they are coming up with anything new.’ (I26, f, US).

6.7.4.8 Proper Care

I asked the question: ‘What are the decisive criteria for proper care of your illness? What do you need as a patient to consider your care as good?’ Through the responses I identified seven categories that are important for the affected, which can be seen in Figure 6.14.

The category *medication*, getting medical treatment for MS, was pointed out by 34% of women and 45% of men in Austria, 21% of women and 19% of men in the US.

The category *social support* was pointed out by 31% of women and 20% of men in Austria, while 11% women and no man in the US gave answers in this category. This category includes statements such as ‘I think its very important that your spouse is 100% supportive at all times. Emotionally and physically it is very important and just accept the thing with the disease.’ (I13, f, US).

The category *organizational support* was pointed out by 28% of women and 20% of men in Austria as well as by 21% of women and 10% of men in the US. This category includes statements such as ‘Once I call the doctors and they get me an appointment right

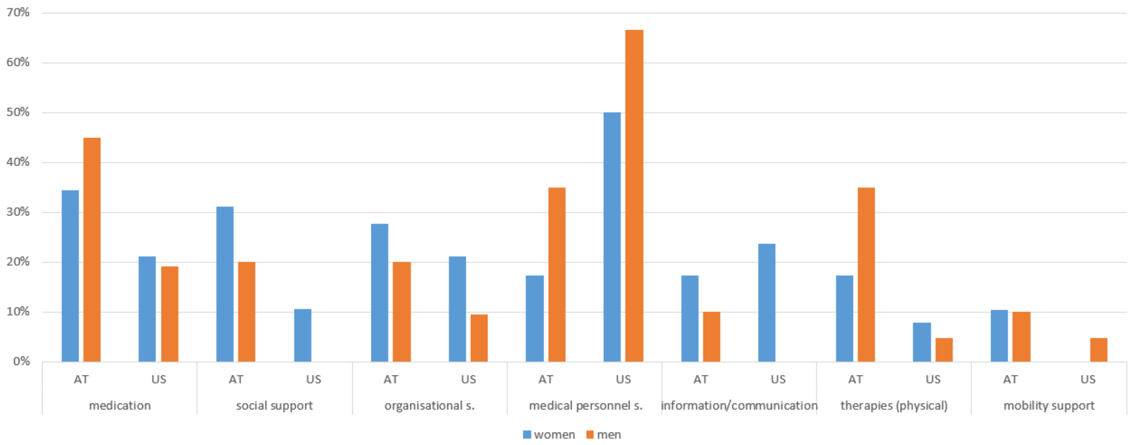

Figure 6.14: Criteria for proper care split by gender and nationality. Women AT N=29, men AT N=20, women US N=38, men US N=21. Answers, such as, 'don't know' or 'nothing is missing' are not included.

away. That means that they care. Because when you get the symptoms, you want to get rid of it right away. So that's, I think, the most important thing.' (I36, f, US).

The category *medical personnel support* includes statements such as 'I need doctors who are personable. I need doctors who I can trust and who are friendly. I really like those folks in this practice, I can talk to them anytime, I can say whatever I want to.' (I12, m, US). 17% of women and 35% of men in Austria answered in this category. In the US, 50% of women and 67% of men answered in this category.

The category *information/communication* includes, for example, statements like 'A support system, a lot of communication. Hopefully there will be more studies. And the communication, even if it's online, needs to be better.' (I55, f, US). This category was pointed out by 17% of women and 10% of men in Austria, by 24% of women and no man in the US.

The category *(physical) therapies* was pointed out by 17% of women and 35% of men in Austria, while similar statements were made by 8% of women and 5% of men in the US. This category includes statements such as 'regular physical therapy would be nice' (I14, f, AT).[14]

The category *mobility support* was pointed out by 10% of both sexes in Austria, by no women and by one men (5%) in the US. Statement in this category are for example 'To have some flexibility, so you can get out a little with public transport, also for those who don't live close to public transport'[15] (I34, f, AT).

6.7.5 Subjective Explanations of Disease Causes

I asked participants about their personal explanation of why they have MS. I wanted to have a closer look on the subjective perception of the disease cause of participants. The

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[14] Regelmäßige Physiotherapie wäre sicher nit schlecht (P lacht), wenn ma des hätten.

[15] Dass man a bissl Flexibilität hat, dass man a bissi rauskommt mit den öffentlichen Verkehrsmittel, für Menschen, die nicht nahe an öffentlichen Verkehrsmittel sind.

question was: ‘What explanation do you have for contracting MS?’

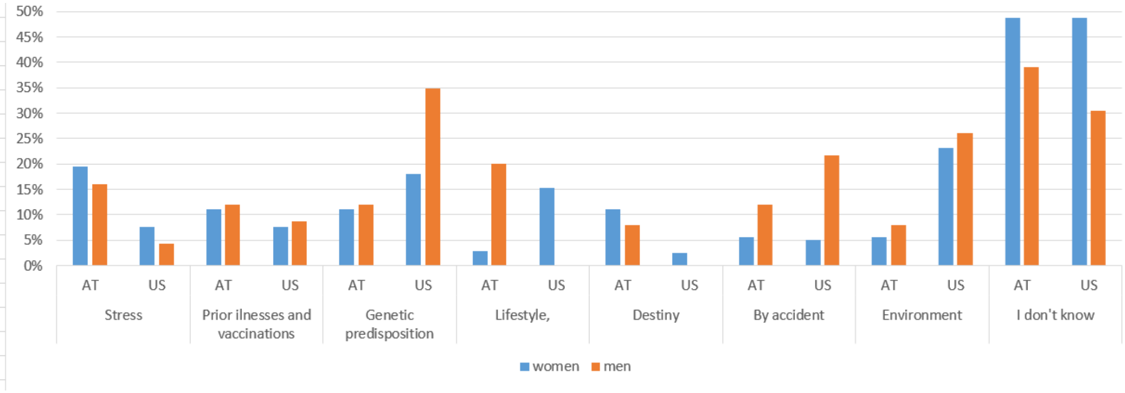

Figure 6.15: How affected explain why they have MS split by gender and nationality. Women AT N=36, men AT N=25, women US N=39, men US N=23.

As can be seen in Figure 6.15, many participants pointed out that they don’t have an explanation for why they have MS (women AT: 49%, men AT: 39%, women US: 49%, men US: 39%). I identified seven additional categories for subjective explanations for the cause of MS.

The category *stress* was pointed out more often by Austrian (19% of women and 16% of men) than by US participant (8% of women and 4% of men). This category includes statements such as ‘I think if there is a weakness in my system, then it is dealing with stress. And I have had lots of stress prior to MS. So, if anything, I would say contributed to it, it would be the stress.’ (I32, f, US).

The category *prior illnesses and vaccinations* was pointed out by roughly 10% of all participants across countries and genders. This category includes statements such as ‘I guess it was triggered by a tic vaccination. I had one, three to four months before I was diagnosed’[16] (I21, m, AT), or ‘I had a bad infectious disease in 1994, had my first flare ups after that.’[17] (I36, m, AT).

The category *genetic predisposition* was pointed out by 11% of women and 12% of men in Austria and by 18% of women and 35% of men in the US. This category includes statements such as ‘I thought about so much, doctors have different opinions. I asked myself, did I do something wrong. I really think it has to be looked at genetics wise, as my whole family has MS.’ (I14, m, US).

The category *lifestyle* was pointed out by 3% of women and 20% of men in Austria and 15% of women and no man in the US. This category includes statements about bad nutrition, having lost too much weight in a short period of time, or traveling too much. One quote was ‘Maybe I was stressed, maybe it was my diet. I was vegan for two and a half years. Maybe I didn’t get enough grease. Maybe it was some soda, that I was drinking for a couple of years, you know, energy drinks when I was studying. That’s all I came up with so far.’ (I20, f, US).

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[16] Hm, [vermeintlicher] Auslöser war eine Zeckenimpfung. Hatte eine drei bis vier Monate, bevor es diagnostiziert worden ist.

[17] Hatte schwere Infektionskrankheit 1994, habe danach erste Schübe bekommen.

The category *destiny* was pointed out by 11% of women and 8% of men in Austria, and by 3% of women and no man in the US. A statement of this category is ‘I guess god spreads different diseases and gives them to those from which he things they can live with it.’[18] (I54, w, AT).

The category *by coincidence* was pointed out by 6% of women and 12% of men from Austria, and 5% of women and 22% of men from the US. This category includes statements such as ‘You get what you get. Life isn’t fair. Everybody has something I guess. This is my something.’ (I58, f, US).

Statements of the category ‘environment’ were mentioned less frequently in Austria (6% of women and 8% of men) than in the US (23% of women and 26% of men). This category includes statements such as ‘I actually don’t know why I have MS. Maybe the environment where we grew up. My sister also has MS. We have different fathers, so I don’t think its genetic. I mean it could be coming from my mum. But there are a lot of cases in the general area where I grew up, of MS. Maybe there was something in the water or in the environment, but I’m not sure.’ (I21, f, US).

6.7.6 Life Changes since being Diagnosed

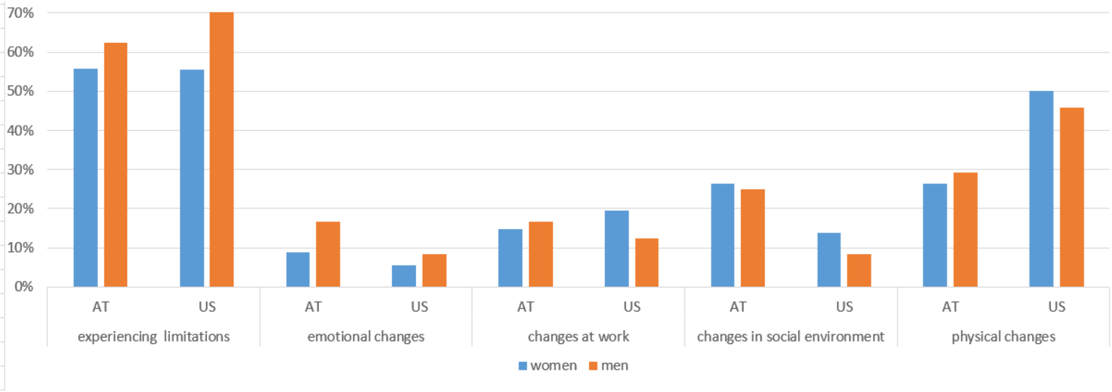

Figure 6.16: How affected describe the changes in their life since being diagnosed with MS split by gender and nationality. Women AT N=34, men AT N=24, women US N=36, men US N=24.

The question ‘Which changes in your life have you perceived since you were diagnosed with MS?’ was answered in five categories, shown in Figure 6.16. The category *experiencing limitations* includes statements such as ‘I feel like I’ve slowed down. The fatigue has made me not being able to do as much as I would like to do. I’m just much more aware of taking care of myself and what can I do to myself and doing what I can to make sure that I don’t have stress, taking care of myself, try to keep myself away from having relapses.’ (32, f, US). This category was pointed out by 56% of women and 63% of men in Austria and by 56% of women and 71% of men in the US.

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[18] Ich glaube, dass Gott verschiedene Krankheiten zum Hergeben hat und er gibt es jenen, von denen er glaubt, dass die damit leben können.

The category *emotional changes* was expressed by 9% of women and 17% of men in Austria and 6% of women and 8% of men in the US. This category includes statements such as ‘I became more indifferent.’[19] (I08, m, AT).

Answers in the category *changes at work* were given by 15% of women and 17% of men in Austria and by 19% women and 13% men in the US. This category includes statements such as ‘It affected my work considerably. I used to have a lot of work and that kind of caused some trouble.’ (I17, m, US), or ‘The job, that’s the biggest one. The fact that I had to stop working. That’s the biggest one. The fact that I couldn’t do the job any more is still very hard for me.’ (I65, f, US).

The category *changes in social environment* was pointed out by more participants in Austria in comparison to US participants (women AT: 26%, men AT: 25%, women US: 14%, men US: 8%). Quotes included in this category are, e.g., ‘I’m definitely less social than I used to be. It feels unpredictable to make plans with other people because often I feel very tired. And it just became very frustrating that you have to cancel plans, so I avoid making plans.’ (I43, f, US).

The category *physical changes* was more often mentioned in the US than in Austria (women US: 50%, men US: 46%, women AT: 26%, men AT: 29%). A statement of this category is ‘I am not as active physically. I am still as active mentally, maybe even more, because I’m determined.’ (I10, f, US). It has to be pointed out that many persons talking about experiencing limitations at the same time pointed out physical changes as well. Nevertheless it made sense to explicitly identify the category of ‘physical changes’ as well.

6.7.7 Significant Experiences with Multiple Sclerosis

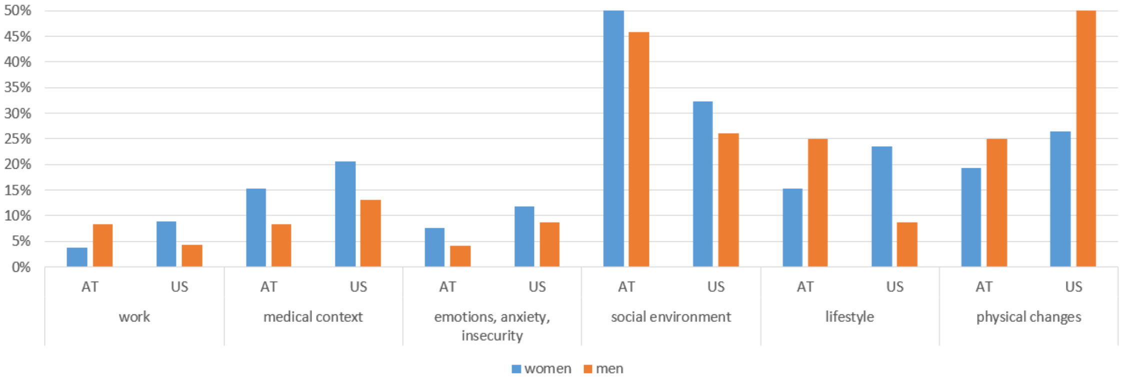

Figure 6.17: How affected describe their most significant experiences since being diagnosed MS split by gender and nationality. Women AT: N=26, men AT: N=24, women US N=34, men US N=23.

I asked participants to describe their most significant experiences resulting from MS. I wanted to get an impression of touching moments that affected had to deal with since having MS. The question was: ‘Please describe your most significant experiences resulting

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[19] Bin gleichgültiger geworden. Kua hin, Kaibl a hin. Schau ma mol, dann segn wir schon.

from MS. What experiences have you had as a person with MS that are most notable?' As can be seen in Figure 6.17, I identified six categories of answers.

Answers in the category *work* were given by 4% of women and 8% of men in Austria and 9% of women and 4% of men in the US. This category includes statements such as 'My lack of being able to work as hard as I used to. Sometimes I just get frustrated because I can't go as fast or do as much as I used to. I don't have the ability to do what I used to do.' (I59, m, US).

The category *medical context* includes experiences made with medical personnel or with medication. One statement of this category is 'Getting chemotherapy [for treating MS], but without any improvement.'[20] (I40, f, AT). Answers in this category were given by 15% of women and 8% of men in Austria and by 21% of women and 13% of men in the US.

The category *emotions, anxiety, insecurity* was more often mentioned in the US than in Austria (women US: 12%, men US: 9%; women AT: 8%, men AT: 4%). Answers in this category are for example 'I guess, whatever is happening during the flare up symptoms. And that brings to the surface uncertainty about the disease. Most notably, I couldn't write and when I wrote, it was like a child. And it was very uncertain at that time—I didn't know, is it gonna be better or not get better. Its always around flare ups. Maybe realizing once again, how uncertain everything is. It could change every moment.' (I23, m, US).

The category *social environment* was pointed out by more Austrian (women: 65%, men: 46%) than American participants (women: 32%, men: 26%). A quote of this category is 'You are not being accepted anymore. My circle of friends has changed. When you can't participate anymore, they leave you. Healthy people can't accept your situation even if they try. Other affected can do that.'[21] (I52, m, AT).

The category *lifestyle* describes significant experiences in identity and the newly adapted lifestyle and was pointed out by 15% of participating women and 25% of participating men in Austria and by 24% of women and 9% of men in the US. A quote of this category is 'There was an identity change for me in thinking of myself of someone with disability. There was a lot of change in my self-perception and personality. It has also just made me more flexible with other people and with myself. Things that bother others, don't bother me, like people being late or just being slower when doing something. Those things don't bother me, because obviously I have to deal with them on my own.' (I44, f, US).

The category *physical changes* was more often mentioned in the US than in Austria (women US: 26%, men US: 57%, women AT: 19%, men AT: 25%). It includes statements such as 'Physically it made me weaker but mentally it made me stronger. I found my voice, it's weird how it happened, but I really did.' (I14, m, US).

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[20] Chemotherapie. War aber ohne Wirkung.

[21] Dass du nicht mehr so akzeptiert wirst. Mein früherer Freundeskreis hat sich geändert. Wenn man nicht mehr mitmachen kann, wenden sie sich ab. Die Pumperlgesunden können das nicht akzeptieren, wollens zwar, aber könnens nicht. Andere Betroffene können das schon.

6.7.8 Hobbies

I asked participants to describe their hobbies to get an idea of haw persons with MS spend their free time respectively which hobbies they have. I classified the categories based on the work by McCabe et al.[47], which identified four categories of activities: exercise, social activities, solidary activities, and work, and supplemented it with one additional category, namely spiritual activities. Among the hobbies mentioned frequently by participants are:

- **Exercise**, such as, sports and physical exercises.
- **Social Activities**, such as spending time with family, traveling, exploring new places, dancing, going out, spending time with friends.
- **Solidary Activities**, such as spending time with pets, art/creativity/handcraft, cultural activities, reading/audiobooks, movies/TV, cooking, playing games, computer, nature/gardening.
- **Volunteer work**.
- **Spiritual Activities**, such as practicing religion.

6.7.9 Social Support

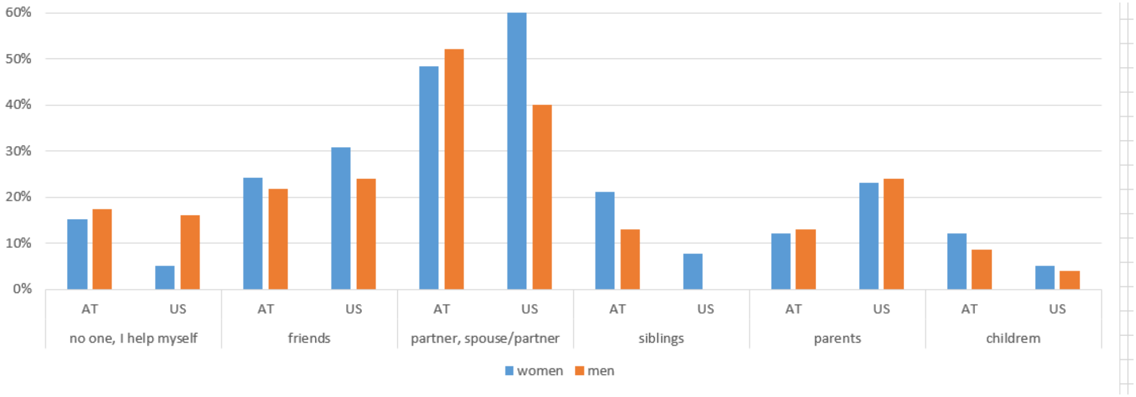

Figure 6.18: Description of who helps out when participants felt at their wits' end split by gender and nationality. Women AT N=33, men AT N=23, women US N=39, men US N=25.

I asked participants 'Who helps you when you are at your wits end?' The main categories identified are presented in Figure 6.18. The category *no one, I help myself* was mentioned roughly equally often, except for women in the US, who answered less frequently in this category (women AT: 15%, men AT: 17%; women AT: 5%, men AT: 16%). The category *friends* was mentioned most often by US women (women AT: 24%, men AT: 23%, women US: 31%, men US: 24%). The category *partner, spouse* is the most frequently mentioned category for all groups, with slightly fewer US men stating support through their partners (women AT: 48%, men AT: 52%, women US: 62%, men US: 40%).

The category *siblings* was more often pointed out in Austria than in the US (women AT: 21%, men AT: 13%, women US: 8%, men US: none). The category *parents* was more often pointed out in the US (women US: 23%, men US: 24%, women AT: 12%, men AT: 13%). The category *children* was more often pointed out in Austria in comparison to the US (women AT: 12%, men AT: 9%, women US 5%, men US: 4%).

Chapter 7

Discussion

The last chapter discussed the results of the study and showed differences in gender and nationality regarding the social and emotional quality of life, mental health variables such as self-esteem or ability to express love, and how affected cope with the disease respectively with stress. It also discussed the benefits participants found because of the disease MS, as well as current needs and experiences of affected.

In this chapter I highlight the most important results and discuss their impact on potential strategies for psychological and social support for affected in the future.

7.1 Quality of Life

I postulated assumptions concerning the social and emotional quality of life with regards to gender differences (there is a gender difference, assumption QoL-1) and nationality (there is a difference in nationalities, assumption QoL-2). I also postulated that there are no difference with respect to patients' perceived health status between genders (QoL-3) and nationalities (QoL-4). Additionally I assumed that there are positive correlations between social-emotional QoL with the BFiMSS subscale *mindfulness* (QoL-5) and with the subscale *new opportunities* (QoL-6).

I identified that women do not differ from men in their social-emotional quality of life, disproving assumption QoL-1. As this study is unique in comparing gender aspects of MS, the result that women and men with MS do not differ in their social-emotional QoL is very important for planning support interventions in the future.

However, with respect to the qualitative data analysis I identified gender differences in the context of QoL. I asked for significant experiences with MS and identified that more women in comparison to men pointed out their most important experiences with MS in the medical context, concerning emotional challenges, as well as experiences in the social environment. More men than women pointed out physical changes as a significant experience with MS. Furthermore I identified that more women in comparison to men described 'changes in the social environment' as an important life change since being diagnosed MS. Men seem to suffer more often from limitations in their lives compared to women.

There are statistical tendencies in distinguishing nationalities in the social-emotional

QoL of participants. US participants reported a lower social-emotional QoL than Austrian participants, which was, however, not significant. Hence I could not verify QoL-2. One reason for a higher social-emotional QoL in Austria could be related to the tighter net of social security and welfare in Austria, as affected don't have to fear to lose insurance, income, housing, etc. Also, Austrians have the benefit of certain services, such as in-patient rehabilitation for extended periods with little cost for the patients while the insurance of many Americans does not cover such services.

Persons in Austria showed a higher disability status (EDSS level) in comparison to US participants, which is likely due to a bias in the survey, as the Austrian leg took place in a rehabilitation-clinic with in-patient care participants, which suggests a more serious condition in comparison to American participants, who were recruited when they visited for regular check-ups. Surprisingly, social-emotional QoL was nevertheless higher in Austria, suggesting that there is no automatic correlation between a high disability status and a low social-emotional QoL.

With regards to the perceived health status I identified no gender differences (verifying QoL-3), and no significant differences in nationality, which means that I could verify assumption QoL-4. As perceived health status correlates strongly with EDSS it can be pointed out that persons have an accurate perception of their health, regardless of gender and nationality. On average study participants rated their health higher than 6 on a scale from 1 (very bad) to 10 (very good). Austrians rated their health status lower than Americans, which is expected due to the lower EDSS score in Austrian participants. These results concur with previous work[21], which has shown that a disease state results in lower physical quality of life. This leads to the conclusion that both EDSS scores and perceived health status are good predictors for health-related quality of life.

However, there are other factors affecting quality of life. I found that persons with a high social-emotional QoL also show high values in mindfulness (verifying QoL-5) and new opportunities (verifying QoL-6), independent of their disease progression. Based on the finding that social-emotional QoL is not automatically associated with physical health I believe that increased support of the social and emotional aspects of the disease can have an impact on the overall patient well-being.

Persons with a high social-emotional QoL also found high benefits in *mindfulness* and *new opportunities* since having MS. The question on causality, however, remains open. Nevertheless, maintaining a high social-emotional QoL should be a goal for affected and their social surrounding.

7.2 Coping and Stress

I postulated the assumptions that there are gender and nationality differences with regards to coping strategies for MS (gender: CaS-1, nationality: CaS-2) and stress (gender: CaS-3, nationality: CaS-4).

I identified gender differences in the ways women and men cope with the disease. In both countries 'acceptance' was pointed out frequently, in Austria by more men than women, in the US by more women than men. 'Denying' was pointed out by more men than women. I thus consider assumption CaS-1 verified. This result is concurrent with literature concerning differences between women and men in the context of coping by Matud[46], who identified differences in stress coping styles between women and men and pointed out that women show emotional and avoidance coping styles more often, while rational and detached coping styles were more common in men. Men showed more emotional inhibition in comparison to women whereas women showed higher values on somatic symptoms and psychological distress in comparison to men. The authors conclude that the stress coping style of women is more emotion-focused in comparison to men. Men showed a rather rational and detached coping style in comparison to women, which is also supported by the results of this study.

A difference was identified in ‘ambivalent, resigned acceptance’ in the context of nationality. In Austria more women than men pointed out this coping strategy, while it was more often mentioned by men in the US, thus verifying assumption CaS-2.

I observed similar differences with regards to strategies for dealing with stress. In general more women than men pointed out ‘physical stress reactions’ and ‘trying to avoid stress’. More men than women pointed out to ‘ignore stress’ (verifying CaS-3).

More women in the US pointed out ‘emotional stress reactions’ in comparison to men in the US. More Austrian than US participants pointed out to have ‘emotional stress reactions’. More participants from the US pointed out ‘positive stress coping activities’ in comparison to Austrian participants, thus verifying assumption CaS-4.

The emotion-focused coping style was pointed out by more women than men. In contrast, more men in comparison to women pointed out more problem focused coping styles such as having strategies available for coping with stress. More women than men pointed out to have no stress coping strategies and more men in comparison to women pointed out ‘positive stress coping strategies’.

This trend is also observable for men coping with the disease. More men deny the illness (same as ‘ignore’ in stress coping strategies). The coping style can thus be seen as a ‘rational, detached style’.

As an outlook for the results identified it should be taken into consideration that women show different coping styles for MS and stress in comparison to men. The gender aspect should be discussed for future psychosocial interventions for coping with MS and stress. Informing affected about gender differences in coping styles could help taking pressure of them, of maybe being different than others.

7.3 Personality and Mental Health

I postulated several assumptions concerning self-esteem and I found differences in gender (PMH-1) and nationality (PMH-2) with regards to self-esteem. I also postulated that there are differences in the ability to love between genders (assumption PMH-3) and nationality (PMH-4). Additionally I postulated that there is a correlation between self-esteem and ‘feeling a purpose in life’ (PMH-5), and between self-esteem and social-emotional QoL (PMH-6), and ability to love and social-emotional QoL (PMH-7).

I found no gender differences in self-esteem, falsifying assumption PMH-1. On the *ability to love* scale I identified gender differences. Women show significant higher values in comparison to men, which confirms assumption PMH-3.

Additionally I identified significant nationality differences on the self-esteem scale. Participants from the US show higher values in self-esteem in comparison to Austrian participants, which proves assumption PMH-2. There are no nationality differences on the *ability to love* scale, proving assumption PMH-4 wrong.

In the qualitative interviews, I identified gender differences in the ‘wish to be different’. Women wish to ‘be more active’ and to be ‘more patient’ more commonly than men. Men on the other hand pointed out more often than women the wish to be in ‘better health’ and the wish to be ‘more social’, which is consistent with the rational, detached style discussed previously.

I found that ‘feeling a sense of purpose in life’ correlates positively with the *self-esteem* scale, proving assumption PMH-5. Schaefer et al.[70] found that persons perceiving a sense of purpose in life show a better emotional recovery from negative stimuli in comparison to persons who do not perceive a purpose in life. Given the results of this study and Shaefer et al.’s insights it appears to make sense to helping patients to feel a sense of purpose in life to improve their social-emotional quality of life.

There is a positive correlation between self-esteem and the social-emotional QoL, proving assumption PMH-6. These results show that QoL and self-esteem are closely connected. To offer better support and to help improve QoL with MS, self-esteem related interventions might be of great importance.

For the last assumption I identified no significant positive correlation of ability to love with the social-emotional QoL. Thus I could not verify assumption PMH-7.

I identified significant gender differences in the ability to express love: men show a lower ability to express love in comparison to women. A potential support service could thus be to teach men about expressing love.

As I identified nationality differences in self-esteem, it would be interesting to understand the causes of these differences to help support affected.

I identified that feeling a sense of purpose in life correlates positively with self-esteem as well as with having a high social-emotional QoL. Focusing on further variables in the context of self-esteem and MS could be future research topics in the field of MS.

7.4 Benefit Finding

I assumed that positive changes in life since diagnosis of MS are perceived by persons with MS independent of gender and nationality (BFiMS-1). I was also interested in the areas of participants lives in which they found benefits since they were diagnosed with MS.

I asked for changes in the seven areas ‘compassion/empathy’, ‘spiritual growth’, ‘mindfulness’, ‘family relations growth’, ‘lifestyle gains’, ‘personal growth’, and ‘new opportunities’.

In the context of benefit finding in MS I identified no significant differences in gender and nationality in these seven subscales. Generally, affected pointed out benefits which they found through MS. I identified benefits especially on the subscales *compassion*, *mindfulness*, *lifestyle gains* and *family relations growth*. On all other subscales at least some benefit was expressed. There were no differences in gender and nationality, proving assumption BFiMSS-1.

For future support for affected it might be of interest to focus on the topics of the subscales and make patients aware that there are ways to see positive aspects of MS. As I identified no differences in gender or nationality, these support services can be offered independent of gender and nationality.

7.5 Social Support

I postulated assumptions concerning the role of social support with regards to gender differences (there is no gender difference, assumption SoSu-1) and nationality (there is no difference in nationality, assumption SoSu-2). I also postulated that there are positive correlations between *social support* and *self-esteem* (assumption SoSu-3), between *social support* and *ability to love* (assumption SoSu-4), between *social support* and *mindfulness* (assumption SoSu-5) and between *social support* and *family relations growth* (assumption SoSu-6).

I found no significant differences in gender (proving assumption SoSu-1) and nationality (proving SoSu-2) on the *social support* scale. Furthermore I identified positive correlations between the *social support* scale and the TPF subscales *self-esteem* (proving assumption SoSu-3) and *ability to love* (proving assumption SoSu-4). The scale *social support* correlates positively with the subscales of benefit finding (BFIMSS) *mindfulness*, yet this tendency was not significant, hence I could not verify assumption SoSu-5. The correlation of *social support* and *family relations growth* was significant, which proves assumption SoSu-6. I thus conclude that offering mindfulness classes and helping improving family relations can be supportive for persons with MS.

Additionally, as social support is closely connected with self-esteem and the ability to express love, offering support for affected to work with their self-esteem and their ability to express love could be supportive in living and organizing a life with MS.

In the qualitative interviews I identified partners and spouses as the most frequent sources of social support, followed by friends and parents.

As these social support sources have to also deal with challenges in their lives, support groups targeted at these caregivers could be beneficial. Although I did not talk to the supportive social network of affected, having MS is not only challenging for the affected, but for the whole family and their social surrounding. Classes about ‘setting boundaries’ and ‘healthy communication’ might be of interest. As I identified no gender and nationality differences in social support, there is no need for targeted offerings.

In general the results identified in the context of gender are consistent with the sociological understanding of gender. Accordingly, the sociological concept of gender the social and cultural meanings of femininity respectively masculinity have to be taken into consideration.

I identified gender differences in coping strategies and the ability to express love. Especially these behavior respectively emotion oriented gender differences, the role of how different men get socialized from women and how different the meanings for expressing emotions are learned, confirm the sociological concept of gender.

7.6 Health Literacy

'Health literacy' encompasses the ways how persons obtain, process, and understand their health information and services. This also includes communication between patients and medical personnel as well as wishes, needs and demands regarding the health care system.

Concerning the question where participants obtain their information about MS 'internet/media' was pointed out most frequently followed by 'medical personnel' in the US. In Austria the main sources for information were 'books, reading, own research' followed by 'internet/media'. This could be attributed to the differences in age of the samples in the two nations or to the varying prevalence of internet use.

The most commonly used medical system used was 'medications', independent of gender and nationality. 'Doctors/hospital' was mentioned mainly in the US, while 'physical therapy' is more prevalent in Austria.

Therapy cooperation is perceived as very important, although men tend to be sceptical about its value. This result shows that especially for men the importance of collaboration should be made a subject of discussion.

I found that 31% of participants in Austria and 44% in the US would be interested in educational courses dealing with topics around MS, indicating a need for more educational courses about MS.

With regards to subjective explanations of the causes of MS, 'stress', 'lifestyle' and 'prior illnesses' were mentioned frequently. Medical personnel should inform patients that the causes of MS are not well understood but that it's likely that MS is caused by a combination of multiple factors and that there is no simple explanation. Patients should be made aware that the disease is not their fault, which could help improving QoL of affected.

Stress might contribute to contracting the disease, but was frequently mentioned as a cause for worsening of symptoms. Courses on dealing with stress could improve patient outcomes.

7.7 The Medical Environment

More than a third of the participants (more women than men) reported negative experience with medical personnel. It is important to be aware of the strong influence on patients' lives that health care professionals posses.

Regarding wishes for services not currently offered, participants pointed out 'therapies and educational support' as well as more 'information' frequently. Additionally wishes addressing the 'medical context' and getting offered a 'cure' for MS were pointed out very often.

Medical personnel should be aware of these wishes and should try to accommodate them in their work with affected, offering more information, more therapies and educational support. As a cure can not be offered at the moment for MS, talking about possibilities to sustain quality of life in MS appears to be very important.

The expectations for a 'proper care with MS' range from 'getting an adequate medication', 'support in managing medical appointments', to 'support from medical personnel' and 'more information'. As the support of medical personnel was frequently pointed out as an important criterion for proper care, educational courses for medical personnel should be offered to develop a way to best support affected. These wishes were pointed out independent of gender and nationality, hence no targeted offerings are necessary.

7.8 Experiences and Changes in Life

I asked participants for positive and negative changes in life since being diagnosed MS. 'Significant experiences in the social environment', 'experiencing boundaries' and 'physical changes' were described most often. Experiences in the social environment include positive as well as negative experiences. Offering patients courses about accepting, dealing with and redefining boundaries in daily life could help improving their social-emotional QoL. Furthermore, focusing on positive life changes since MS could help reframing perceived life situations of affected.

7.9 Limitations

In the course of this survey I compared two samples taken in different countries, namely Austria (Styria) and the US (Massachusetts). As a consequence of different languages, the questionnaires I used had to be adapted. While I took great care to properly translate the questionnaires and to adapt the categories where necessary, it is possible that some shift in meaning for certain answers occurred. Challenges also arose when comparing, for example income or educational level, which do not have trivial mappings between the countries.

Translating quantitative questionnaires as well as qualitative interviews to an other language includes the danger of different biases[80]). I used the following strategies to avoid these biases.

1. **Construct Bias**: The question to address is whether the same construct is measured in both cultures, whether the cultural meaning in the countries is captured correctly. As Austria and Americans are both industrialized western countries with a shared cultural background and are similar concerning their educational system, socialization, and their understanding as well as treatment of MS, this bias is likely to not be severe. Great care was taken to avoid any language biases (see Chapter 4.4).

2. **Method Bias**: According to van de Vijver[80], three different subtypes of method biases are possible: sample bias, instrument bias, and administration bias. Sample bias asks whether the same sample size and similar sample characteristics are chosen between the comparable countries. Instrument bias captures whether the questionnaires and interviews as well as the response procedure (response bias) are understood equally in both cultures. Administration bias describes communication problems between interviewer and interviewee. As in this thesis the survey was conducted by the same person in both countries and the interviewer spoke both languages fluently, this bias has likely no influence. It can be concluded that method biases were controlled for.

3. **Item bias** or differential item functioning: this bias refers to different item meaning in different cultures. To avoid the item bias all survey material was translated and re-translated and adapted to account for cultural differences.

Another potential problem is a gender bias. Gender biases can arise when using non-inclusive formulations, e.g., when not using masculine and feminine generics adequately. To counteract this bias, all aspects of this study used gender-inclusive wording.

Additionally, the recruitment modalities differed between the two legs of the survey. While in Austria the sample was taken with stationary patients of a neurological rehabilitation clinic for MS, study participants in the US were recruited when they had an out-patient MS checkup.

These differences in recruitment modalities were caused by the absence of an equivalent facility in the USA, as long-term rehabilitation is rather uncommon in the USA. This difference has likely caused the worse average health status of Austrian participants. While I did control for disease progression in all of the statistical analysis, the qualitative results might be biased by this difference in health status.

As the age distributions of the two samples is different, the comparability of the samples could be questioned. To counteract this as good as possible, age was used as a covariate in the statistical data analyses.

As I did not use a control group of healthy subjects, I cannot make causal inferences about the relationship of the discovered behavior and the disease. This, however, was not the intention of the study.

While I did not achieve a balanced gender ratio, probably due to the fact that women are more frequently affected by MS than men, the ratio of 78 women to 50 men is sufficient to find statistically meaningful differences.

Chapter 8

Conclusion and Outlook

In this thesis I researched differences in gender and nationality in the psychological and social context of MS. My hope is that the data and insights collected in the study described in this text, can help develop interventions to improve the social and emotional quality of life of affected in the future.

Concerning their social-emotional QoL women do not differ from men, which is a novel insight about MS, as no research is available about gender and MS. As I identified no differences in gender in the context of social-emotional QoL I can assume that criteria for social and emotional QoL are universal for affected. This can inform the development of psychological and social interventions for MS.

I showed that women show a higher ability to express love than men. Women and men also differ in their coping strategies, in how they deal with MS and stress, in their health literacy, their wishes, and their experiences with MS. Gender differences have to be understood in a broader sociological context as well, influenced by the culture persons live in, by societal norms and by the socialisation of each person.

I found differences regarding nationality: Not only do Austrian affected differ from US participants in their social-emotional QoL, but they are also different regarding their mental health. I furthermore discovered differences between participants from Austria and the US regarding coping, health literacy and experiencing MS.

Future interventions can be oriented on these national differences to identify strategies for recommendations for making living with MS easier. Learning from each other may widen the own perception of living MS for affected.

8.1 Recommendations

Based on my findings and on insights published previously, I suggest to develop psychological and social interventions in three core areas to improve the quality of life for the MS population.

Coping I identified several positive coping strategies for dealing with MS and with stress. ‘Accepting’ MS, ‘being active’, ‘being religious’, and ‘education’ were pointed out as important coping strategies for MS. ‘Being active’ includes activities such as doing mantras, meditation or playing an instrument.

I suggest offering courses about ‘acceptance’ and ‘mindful activities to deal with MS’. A course about ‘acceptance’ should discuss the importance of accepting something in life, the consequences of accepting something in life and fears accompanying acceptance. A course about ‘doing things mindfully in life’ should deal with how to live and accept life moment by moment without hurrying. Affected should be taught in accepting the own speed and not forcing themselves to be faster. Being mindful about life and the own speed can help to better cope with MS and stress and being oriented on different aspects in life, not only on the burden with MS.

Also, stress coping strategies and activities were pointed out. Among them were thinking about the problem and visualizing a solution, making a plan for how to solve the problem, taking a step back and writing down solution options. Positive stress coping activities mentioned include ‘being creative’, ‘schedule times with friends’, or ‘do activities in groups’ such as ‘joining a book club’.

These strategies and activities for dealing with stress also include being mindful in reacting to stress and executing activities mindfully. In this context I recommend mindfulness classes for affected to better cope with MS and stress and to execute planned activities more mindfully.

Communication I identified that more than a third of the participants had negative experiences with medical personnel. Negative experiences with doctors or nurses can lead to a lack of trust or the feeling of being misunderstood. Also, problems with scheduling doctor’s appointments were mentioned frequently.

Additionally wishes in the medical context were pointed out in the qualitative interviews. For example, affected expressed doubt that research on MS is done seriously and wished for improvements in this area, or that doctors do not see affected as a whole and do not accompany them on their way. Furthermore the wish for more support from medical personnel was pointed out.

Based on these results I suggest offering courses targeted at the **medical personnel** on how to improve communication with patients about these and similar issues.

The need for more social support was pointed out frequently. Based on this result I suggest offering courses for **affected** to learn how to express what they want and how to express it without a guilty conscience.

Self-Management A combination of my results and those from the literature leads me to recommend developing psychological and social interventions regarding self-management.

Audulv[4] found four patterns of self-management with a chronic illness and participants often used more than one pattern simultaneously. A ‘consistent pattern’ is used to, e.g., manage long term medication, an ‘episodic pattern’ is employed to manage exercise. An ‘on demand pattern’ relates to managing crisis related to the health situation and a ‘transitional pattern’ includes managing every day changes due to the illness.

Additionally the author points out the necessity to be aware of what could influence the process of self-management behavior, such as health believes or the role of social support. Sauter et al.[69] and Packer et al.[26] developed an effective six week intervention for managing fatigue. For stress management Moss-Morris[49] identified that cognitive behavioral therapies are more effective than supportive listening to manage distress.

For the future, self-management instruments should be offered to support the chronically ill. They should be developed together with affected and their individual needs. Self-management instruments could be developed in the context of managing the medication, bad episodes with MS, exercise, household activities, leisure time, work, lifestyle (such as nutrition), stress, emotions, identity, or fatigue.

Wagner et al.[81] analyzed the effects of classical cognitive behavioral therapy face-to-face in comparison to an internet guided self help support in persons with bulimia nervosa. They found no difference between both ways of offering guidance. This suggest that offer both, support interventions face-to-face, in group settings, but also online are sensible approaches.

Improving Quality of Life I identified that affected with a high social-emotional QoL also have a high self-esteem as well as a high ability to express love. These results indicate that social-emotional QoL is closely connected to personality topics such as self-esteem or the ability to express love. As a consequence I suggest offering psychological classes and face-to-face support for affected in the context of personality. Offering support regarding increasing 'self-esteem' and 'ways to express love' would be meaningful interventions for affected.

Psychotherapy and counseling by clinical- and health psychologists as well as social workers should be offered as a default intervention for affected.

Additionally, I identified that persons with a high social-emotional QoL found 'new opportunities' as benefit of having MS and became more 'mindful' since having MS. Based on these results affected should be made aware of the importance of living a mindful live and focusing on new opportunities with MS instead of concentrating on only the burden that comes with MS. In the future psychological and social interventions should include theoretical educational courses about these topics as well as practical self-management recommendations.

8.2 Future Work

Through my research I gained deep insights into the world of having to live with MS in Austria and Massachusetts. For future work it would be of great importance to get more such information from more countries with a high MS prevalence. Comparing the various cultural approaches can refine the information of how affected deal with living MS.

Additionally, a longitudinal study could give deep insights in how psychological and social patterns of MS, burdens and challenges, develop and which factors might affect them.

As I identified nationality differences in self-esteem further research is necessary to understand how the higher self-esteem in the US helps supporting MS patients in daily life. Focusing on further variables in the context of personality and MS could be future research topics in the field of MS.

Finally, focusing on young MS patients would open up possibilities to discover problems of dealing with MS in the early stages. I also believe that for this phase customized psychological and social support is likely to have the highest overall impact on the patients' quality of life.

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Appendix A

Survey Information and Consent Form

On the following pages the survey information and consent form in both, English and German is reproduced.

Psychosocial Aspects Affecting the Quality of Life of Persons with Multiple Sclerosis

Dear Survey Participant,

as part of my PhD thesis an intercultural research is conducted in Austria and Boston to identify differences and shared traits in people with Multiple Sclerosis concerning their Quality of Life.

The following survey investigates the needs of the affected participant, changes in their quality of life since diagnosis and the coping strategies of women and men who suffer from MS.

64 people of either sex aged between 20 and 57 are surveyed using quantitative questionnaires as well as face-to-face interviews in each country.

Your participation is voluntary. The survey will take about 50 minutes to complete.

The main goal of the survey is to better psychosocially attend to and care for people with MS and to support them in their capabilities and potentials.

My name is Heidemarie Lex, I am a clinical and health psychologist as well as a researcher in Multiple Sclerosis.

I suffer from Multiple Sclerosis myself and am available anytime for further questions
Cell: (857)2843080; Email: hlex@bidmc.harvard.edu.

Thank you for your participation!

FOR CCI USE ONLY
Approved by the Beth Israel Deaconess Medical Center Committee on Clinical Investigations:

Administrator:__________________________________

Consent Approval Date: __________________

Protocol Number: _________________

Study Approval Expiration Date: __________________

INFORMED CONSENT FORM TO TAKE PART IN A RESEARCH STUDY

SUBJECT'S NAME:

TITLE OF RESEARCH PROTOCOL: Psychosocial Aspects Affecting Quality of Life in Persons with Multiple Sclerosis
Gender differences in dealing with the disease. An intercultural comparison

PRINCIPAL INVESTIGATOR: **Jacob Sloane**

CO-INVESTIGATORS: **Sana Syed, Heidemarie Lex, Marion Stein, Lindsay Sklover**

PROTOCOL NUMBER: **2013-P-000212/1**

INTRODUCTION:

You are invited to take part in a research study about Quality of Life and Multiple Sclerosis. This study will survey psychosocial aspects of Quality of Life in people with multiple sclerosis (MS).
You are being asked to take part in this study because you carry a diagnosis of Relapsing-Remitting Multiple Sclerosis (RRMS), Primary Progressive Multiple Sclerosis (PPMS) or Secondary Progressive Multiple Sclerosis (SPMS).

- This is a research study;
- Your participation is voluntary;
- A research study includes only people who choose to take part;
- You may or may not benefit from participating in the study. However, your participation may help others in the future as a result of knowledge gained from the research;
- You may leave the study at any time;
- If you choose not to take part, or if you leave the study, your decision will in no way harm your relationship with any member of the research team or any other individuals at Beth Israel Deaconess Medical Center.

Please read this consent form carefully and ask the investigators or study staff to explain any words or information that you do not clearly understand. Once you read this consent form and understand what your participation in this study will involve, you will be asked to sign this form if you wish to take part. You will be given a signed copy of the form to keep for your records.

DISCLOSURE OF SPECIAL INTERESTS OF BIDMC AND INVESTIGATORS

SUBJECT'S NAME:
TITLE OF RESEARCH PROTOCOL: Psychosocial Aspects Affecting Quality of Life in Persons with Multiple Sclerosis Gender differences in dealing with the disease. An intercultural comparison
PRINCIPAL INVESTIGATOR'S NAME: **Jacob Sloane**
CO-INVESTIGATORS: **Sana Syed, Heidemarie Lex, Marion Stein, Lindsay Sklover**
PROTOCOL #: 2013-P-000212/1

This study is being conducted by Dr. Jacob Sloane. There is no funding agency in this study. Neither BIDMC nor Dr. Sloane, Dr. Sana Syed, Dr. Marion Stein, and Heidemarie Lex have any additional interests in this research project.

WHOM TO CONTACT IF YOU HAVE QUESTIONS OR PROBLEMS

If you have any questions, concerns or complaints about this research or experience any problems, you should contact Heidemarie Lex at [617] 667-3742.

PURPOSE

The main purpose of this survey is to identify psychosocial factors affecting quality of life in persons with Multiple Sclerosis.

We also hope to learn about differences in coping strategies between women and men as well as possible intercultural differences in coping strategies in persons with Multiple Sclerosis.

Affected persons will be asked about different aspects of living with MS in an interview and will be asked to complete some questionnaires.
.

STUDY PARTICIPANTS

Approximately 64 people, both women and men, between 20 and 57 years of age, will take part in this study at Beth Israel Deaconess Medical Center.

DESCRIPTION OF STUDY DETAILS

This scientific survey is a novel project aimed to research the quality of life of Multiple Sclerosis patients.
The primary prerequisite of participating in this survey is that you sign a written consent form that your participation is voluntary.
The purpose of the survey is to ask persons with MS about the impact of the diagnosis of MS on their mood, social networks and activities. There are also questions aimed to investigate the various compensatory mechanisms employed by patients to deal with their illness on a daily basis.
On the basis of this survey results it will be possible to improve psychosocial assistance available and to treat persons with Multiple Sclerosis from the time of diagnose.

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Please only sign the form when you fully understood mode and process of the survey, when you are ready to participate and when you have read about your rights.

The total study visit will last about 50 minutes.

If you agree to participate in this survey, you will be asked to read and sign this consent form. After you sign the consent form, the following things will happen:

First you will be given a paper questionnaire and will be asked to complete it to the best of your ability. The survey conductor will be present in the room with you and can answer any questions you may have as you complete the questionnaire.
The questionnaire will take you approximately 25 minutes to complete.

The questionnaire is followed by an interview with the study conductor. The study conductor will ask you to describe life changes and new challenges since your diagnosis.
This interview will take you approximately 25 minutes as well.

RISKS AND DISCOMFORTS

There are no physical risks or discomforts associated with conducting the interview and completing the questionnaires.
As a result of your participation in this survey, you are at risk for side effects of being emotionally attached, having the feeling of anxiety or sadness, followed by or during the interview. This could be because the questions deal are personal and participants take an introspective look at their health and life situation.

Psychological Stress:

Some of the questions we will ask you as part of this study may make you feel uncomfortable. You may refuse to answer any of the questions and you may take a break at any time during the study. You may stop your participation in the study at any time. Should you have any additional questions or concerns during or after the study visit, please contact the study staff.

CONFIDENTIALITY

Information learned from your participation in this study and from your medical record may be reviewed and photocopied by the Committee on Clinical Investigations, the Human Subjects

Protection Office and others involved in research administration of the Beth Israel Deaconess Medical Center with protection of confidentiality so far as permitted by applicable law. Information resulting from this study and from medical record may be used for research purposes and may be published; however, you will not be identified by name in such publications. Your data is stored onsite in a secure place with restricted access till the time of statistical analysis.

The interviews are taped and transcribed afterwards for the qualitative data analysis after which the tapes are destroyed. The data is documented anonymously and the digital data is stored on password protected and encrypted devices per the guidelines of Beth Israel in order to maintain privacy.

POSSIBLE BENEFITS

We do not anticipate any direct benefit. From the information collected in this survey, guidelines will be developed for targeted psychosocial therapy to help patients with MS and their respective caretakers. The specific parameters analyzed include gender, age and course of MS disease. This information will allow us to cater to the individual needs of patients based on differences in these characteristics. We hope that assessing gender differences in coping strategies and quality of life will provide critical information for individualized psychosocial care from the earliest stages of the disease.

OTHER AVAILABLE OPTIONS

Taking part in this study is voluntary. Instead of being in this study, you have the option to not participate in the study.

This research study is not meant to diagnose or treat medical problems. Participation in this research study does not take the place of routine physical examinations or visits to your regular doctor.

We recommend that you discuss these and other options with the investigator and your regular doctor so that you can make a well-informed decision about participating in this study.

IF YOU DECIDE NOT TO TAKE PART IN THE STUDY

Participation in this study is voluntary. You have the right to decide not to take part in this study. If you choose to participate, you have the right to leave the study at any time. Your decision to not participate will not result in any penalties or loss of benefits to you. The investigators will tell you

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about new information that may affect your willingness to stay in this study.

If you decide not to participate in the study or decide to leave the study early, your decision will not affect your relationship with the research team or any other individual at Beth Israel Deaconess Medical Center.
There are no risks to leaving the study before it is completed.

INVESTIGATORS RIGHT TO STOP THE STUDY

The investigators have the right to end your participation in this study if they determine that you no longer qualify to take part, or if it would be dangerous for you to continue, or if you do not follow study procedures as directed by the investigators. Beth Israel Deaconess Medical Center or the funding source may stop the study at any time.

AUTHORIZATION FOR USE AND DISCLOSURE OF YOUR PROTECTED HEALTH INFORMATION

As part of this study, we will be collecting, using and sharing with others information about you. Please review this section carefully as it contains information about the federal privacy rules and the use and disclosure of your information.

PROTECTED HEALTH INFORMATION [PHI]

By signing this informed consent document, you are allowing the investigators and other authorized personnel to use [internally at BIDMC] and disclose [to people and organizations outside the BIDMC workforce identified in this consent] health information about you. This may include information about you that already exists (for example: your medical records and other sources of health information, demographic information, the results of any laboratory tests) as well as any new information generated as part of this study. This is your Protected Health Information.

PEOPLE/GROUPS AT BIDMC WHO WILL SHARE AND USE YOUR PROTECTED HEALTH INFORMATION

Your Protected Health Information may be shared with and used by investigators listed on this consent form as well as the supporting research team [i.e. research assistants and coordinators, statisticians, data managers, laboratory personnel, pharmacy personnel, administrative assistants], and may also be shared and used by other health care providers at BIDMC who have treated you in the past and have information relevant to the research, or who provide services to you in connection with the research. Your Protected Health Information may also be shared with the members and staff of the Committee on Clinical Investigations of Beth Israel Deaconess Medical Center, which is

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responsible for reviewing studies for the protection of the research subjects.

PEOPLE/GROUPS OUTSIDE OF BIDMC WITH WHOM YOUR PROTECTED HEALTH INFORMATION WILL BE SHARED

We will take care to maintain confidentiality and privacy about you and your Protected Health Information. We may share your Protected Health Information with the following groups so that they may carry out their duties related to this study:

- The funding source and/or sponsor of this study and, where applicable, the people and companies that the funding source and/or sponsor use to oversee, administer, or conduct the research (for example, clinical research organizations are companies that are sometimes hired by research sponsors to help manage and run a clinical research study)
- The other hospitals and medical centers taking part in this study and research collaborators at those institutions
- Any external health care providers who provide services to you in connection with this research
- Laboratories not affiliated with BIDMC that are involved in conducting tests related to the research
- Statisticians and other data monitors not affiliated with BIDMC
- The members and staff of any other IRBs (beyond the BIDMC Committee on Clinical Investigations) that oversee the research
- Centralized data collectors
- Your health insurance company
- The Food and Drug Administration [FDA], the Department of Health and Human Services [DHHS], the National Institute of Health [NIH], the Office for Human Research Protections [OHRP], and other federal and state agencies that may have jurisdiction over the research
- Hospital and Clinical Research Accrediting Agencies
- Data and Safety Monitoring boards that oversee this study (if applicable)

Those who receive your Protected Health Information during the course of the research may not be required by the federal privacy regulations to protect it, and they may make further disclosures to others and use your information without being subject to penalties under those laws.

WHY WE ARE USING AND SHARING YOUR PROTECTED HEALTH INFORMATION

The main reason for using and sharing your Protected Health Information is to conduct and oversee the research as described in this Informed Consent Document. There are many other reasons beyond the research for which BIDMC may use or disclose your Protected Health Information. Not all of these reasons require your express written authorization. For example, we will use and share your Protected Health Information to ensure that the research meets legal, institutional and accreditation requirements and to conduct public health activities. The various ways in which BIDMC may use and disclose your protected health information without your authorization are explained in a document called the Notice of Privacy Practices. If you have not received a copy of BIDMC's Notice of Privacy Practices, please ask us for one and review it before signing this form. In addition to signing this document, you may also be asked to sign a BIDMC General Agreement form acknowledging that you have received the BIDMC Notice of Privacy Practices.

NO EXPIRATION DATE – RIGHT TO WITHDRAW AUTHORIZATION

Your authorization for the use and disclosure of your Protected Health Information in this Study shall never expire. However, you may withdraw your authorization for the use and disclosure of your Protected Health Information at any time provided you notify the Principal Investigator in writing. If you would like to take back your authorization so that your Protected Health Information can no longer be used in this study, please send a letter notifying the Principal Investigator of your withdrawal of your authorization to Dr. Sloane at 330 Brookline Ave, KS 211 Boston, MA 02215. Please be aware that the investigators in this study will not be required to destroy or retrieve any of your Protected Health Information that has already been used or disclosed before the Principal Investigator receives your letter, and they are permitted to continue to use and disclose your previously collected information as necessary to complete the research.

REFUSAL TO SIGN

Your clinical treatment may not be conditioned upon whether you sign the Authorization for Research. However, if you choose not to sign this informed consent document and authorization for the use and disclosure of your Protected Health Information, you will not be allowed to take part in the research study.

RIGHT TO ACCESS AND COPY YOUR PHI

If you wish to review or copy your Protected Health Information as it is made part of your medical record, you may do so after the completion or termination of the study by sending a letter to the Principal Investigator requesting a copy of your Protected Health Information. You may not be allowed to inspect or copy your Protected Health Information until this study is completed or terminated.

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ADDITIONAL CONTACT FOR QUESTIONS OR CONCERNS
You may contact the Human Subjects Protection Office at [617] 667-0469 in the event that you would like to obtain information or to offer input about the research study. This office is independent of the investigator or investigator's research staff and can also assist with questions relating to your rights as a participant in research, which may include questions, concerns or complaints about your participation in the study.

ICF Revision Date:September 27, 2013
Initial Submission May 14, 2013

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THE FOLLOWING PARAGRAPHS CONTAIN SOME STANDARD INFORMATION WHICH GENERALLY APPLIES TO INDIVIDUALS PARTICIPATING IN A RESEARCH STUDY.

CONSENT FORM FOR CLINICAL RESEARCH

I have read the previous page[s] of the consent form and the investigator has explained the details of the study. I understand that I am free to ask additional questions.

If I wish additional information regarding this research and my rights as a research subject, or if I believe I have been harmed by this study, I may contact the Human Subjects Protection Office (HSPO) at [617]667-0469

I am aware that this is a research project and that unforeseen side effects may occur.

I understand that the Beth Israel Deaconess Medical Center has no formal program for compensating patients for medical injuries arising from this research. Medical treatment will be provided for injuries at the usual charge to me or to my insurer unless payment is otherwise provided for in this consent form.

I understand that participation in this study is voluntary and I may refuse to participate or may discontinue participation at any time without penalty, loss of benefits, or prejudice to the quality of care which I will receive.

I acknowledge that no guarantees have been made to me regarding the results of the treatment involved in this study, and I consent to participate in the study and have been given a copy of this form.

______________________________ _________________________
Signature of Subject or Date
Legally Authorized Representative
(Parent if the subject is a minor)

____
Relationship of Legally Authorized Representative to Subject

The subject has been given the opportunity to read this consent form and to ask questions before signing, and has been given a copy.

____
SIGNATURE OF INVESTIGATOR/Co-Investigator DATE

SUBJECT'S NAME:
TITLE OF RESEARCH PROTOCOL: Psychosocial Aspects Affecting Quality of Life in Persons with Multiple Sclerosis Gender differences in dealing with the disease. An intercultural comparison
PRINCIPAL INVESTIGATOR'S NAME: **Jacob Sloane**
CO-INVESTIGATORS: **Sana Syed, Heidemarie Lex, Marion Stein, Lindsay Sklover**
PROTOCOL #: 2013-P-000212/1

____
PRINT INVESTIGATOR'S/Co-Investigator's NAME

THE FOLLOWING SECTIONS ARE NOT NEEDED FOR ALL STUDIES AND SHOULD BE UTILIZED AS INDICATED:

If the subject is able to speak and understand English but is not able to read or write

I was present during the entire oral presentation of the informed consent and witnessed the subject's agreement to participate in the study.

Signature of Witness: ____________________________________

Printed Name of Witness: ____________________________________

Date: ________________

If the subject is able to understand English but is not physically able to read or write or see

I was present during the entire oral presentation of the informed consent and witnessed the subject's agreement to participate in the study.

Signature of Witness: ____________________________________

Printed Name of Witness: ____________________________________

Date: __________________

If the subject is not English speaking and signed the translated Short Form in lieu of the English consent document.

SUBJECT'S NAME:	
TITLE OF RESEARCH PROTOCOL: Psychosocial Aspects Affecting Quality of Life in Persons with Multiple Sclerosis Gender differences in dealing with the disease. An intercultural comparison	
PRINCIPAL INVESTIGATOR'S NAME: **Jacob Sloane**	
CO-INVESTIGATORS: **Sana Syed, Heidemarie Lex, Marion Stein, Lindsay Sklover**	
PROTOCOL #: 2013-P-000212/1	

As someone who understands both English and the language spoken by the subject, I interpreted, in the subject's language, the researcher's presentation of the English consent form. The subject was given the opportunity to ask questions.

Signature of Interpreter: ____

Printed name of Interpreter: ____

Date: ____________________

Psychosoziale Aspekte, die auf die Lebensqualität von Menschen mit Multipler Sklerose wirken

Lebensstil- und Geschlechtsunterschiede im Umgang mit und der Bewältigung von Multipler Sklerose

Dissertation an der Medizinischen Universität Graz
MMag.ª Heidemarie Lex

Liebe Reha-Besucherin, lieber Reha-Besucher,

viele Menschen mit einer chronischen Erkrankung berichten markante Lebensveränderungen nach einem ersten völligen Zusammenbruch nach Diagnosestellung.
In dieser Erhebung geht es darum, Menschen mit Multipler Sklerose über ihr Leben mit MS, ihrer Lebensqualität sowie ihrer Lebensveränderung seit der Erkrankung, zu befragen.
Die Befragung wird 60 Personen im Alter zwischen 20 und 49, die seit mindestens einem Jahr MS diagnostiziert sind, umfassen und hier im Hause in ruhigem Umfeld stattfinden. Da Frauen und Männer eine unterschiedliche Herangehensweise haben, mit (negativen) Lebensereignissen umzugehen, soll in dieser Befragung speziell auf diese Unterschiede im Umgang mit der Erkrankung von Frauen und Männern Bezug genommen werden.
Das Gespräch wird in etwa 50 Minuten dauern und eine Teilnahme an der Befragung ist selbstverständlich freiwillig.

Ziel dieser Erhebung ist es, zukünftig Menschen mit MS besser psychosozial begleiten und betreuen zu können und eine gezielte Förderung der eigenen Ressourcen Betroffener zu fördern.

Mein Name ist MMag.ª Heidemarie Lex, ich bin Klinische und Gesundheitspsychologin und führe die Befragung durch. Ich habe selbst MS und stehe zu Fragen zur Erhebung gern zur Verfügung (auch telefonisch: 0043 676 68 54 008 oder per mail: heidi.lex@gmail.com).

Ich würde mich sehr freuen, Sie als ErhebungsteilnehmerIn begrüßen zu dürfen.
Sollten Sie sich für eine Teilnahme entscheiden, geben Sie dies bitte auf Ihrer Station bekannt oder kontaktieren Sie mich persönlich.

Herzlichen Dank und schönen Aufenthalt,
Heidemarie Lex

PatientInneninformation und Einwilligungserklärung zur Teilnahme an der Erhebung

<u>Psychosoziale Aspekte, die auf die Lebensqualität von Menschen mit Multipler Sklerose wirken</u>

Lebensstil- und Geschlechtsunterschiede in Verarbeitung und Umgang mit der Erkrankung

Sehr geehrte Teilnehmerin, sehr geehrter Teilnehmer!

Ich lade Sie ein, an der oben genannten Erhebung teilzunehmen. **Ihre Teilnahme an dieser Befragung erfolgt freiwillig. Sie können jederzeit ohne Angabe von Gründen die Erhebung abbrechen. Die Ablehnung der Teilnahme oder ein vorzeitiges Ausscheiden hat keine nachteiligen Folgen für Sie.**

Erhebungen sind notwendig, um verläßliche neue wissenschaftliche Forschungsergebnisse zu gewinnen. Unverzichtbare Voraussetzung für die Durchführung einer Befragung ist jedoch, daß Sie Ihr Einverständnis zur Teilnahme an dieser schriftlich erklären. Bitte lesen Sie den folgenden Text sorgfältig durch und zögern Sie nicht, Fragen zu stellen.

Bitte unterschreiben Sie die Einwilligungserklärung nur

- wenn Sie Art und Ablauf der Befragung vollständig verstanden haben,
- wenn Sie bereit sind, der Teilnahme zuzustimmen und
- wenn Sie sich über Ihre Rechte als TeilnehmerIn an dieser Befragung im Klaren sind.

Zu dieser Erhebung sowie zur PatientInneninformation und Einwilligungserklärung wurde von der zuständigen Ethikkommission eine befürwortende Stellungnahme abgegeben.

Was ist der Zweck der Erhebung?

Der Zweck dieser Erhebung ist, Menschen mit Multipler Sklerose über ihre Lebensqualität und wahrgenommene Veränderungen seit der Erkrankung zu befragen. Zukünftig soll es aufgrund der erfassten Daten möglich sein, Menschen mit Multipler Sklerose psychosozial besser begleiten und behandeln zu können und eine Aktivierung ihrer eigenen Ressourcen zu fördern.

Wie läuft die Befragung ab?

Diese Erhebung wird in der Reha-Klinik Judendorf-Straßengel durchgeführt, und es werden insgesamt ungefähr 60 Personen mit Multipler Sklerose daran teilnehmen.

Ihre Teilnahme an dieser Befragung wird voraussichtlich 50 Minuten dauern.

In welcher Weise werden die im Rahmen dieser Erhebung gesammelten Daten verwendet?

Sofern gesetzlich nicht etwas anderes vorgesehen ist, haben nur die Prüferin und deren MitarbeiterInnen Zugang zu den vertraulichen Daten, in denen Sie namentlich genannt werden. Diese Personen unterliegen der Schweigepflicht.

Die Weitergabe der Daten erfolgt ausschließlich zu statistischen Zwecken und Sie werden ausnahmslos darin nicht namentlich genannt. Auch in etwaigen Veröffentlichungen der Daten dieser Erhebung werden Sie nicht namentlich genannt.

Möglichkeit zur Diskussion weiterer Fragen

Für weitere Fragen im Zusammenhang mit dieser Befragung steht Ihnen die Befragungsleiterin gern zur Verfügung. Auch Fragen, die Ihre Rechte als TeilnehmerIn an dieser Befragung betreffen, werden Ihnen gerne beantwortet.

Name der Kontaktperson: MMag.ª Heidemarie Lex

Ständig erreichbar unter: 0043 676 68 54 008

13. Einwilligungserklärung

Name PatientIn in Druckbuchstaben: ....

Geb.Datum: .... Code: ....

Ich erkläre mich bereit, an der Erhebung „Lebensqualität und Multiple Sklerose“ teilzunehmen.

Ich bin von Frau MMag.ª Lex ausführlich und verständlich über die Befragung, mögliche Belastungen sowie über Wesen, Bedeutung und Tragweite der Erhebung, sich für mich daraus ergebenden Anforderungen aufgeklärt worden. Ich habe darüber hinaus den Text dieser PatientInnenaufklärung und Einwilligungserklärung, die insgesamt 3 Seiten umfaßt gelesen. Aufgetretene Fragen wurden mir von Frau MMag.ª Lex verständlich und genügend beantwortet. Ich hatte ausreichend Zeit, mich zu entscheiden. Ich habe zur Zeit keine weiteren Fragen mehr.

Ich werde den Anordnungen, die für die Durchführung der Befragung erforderlich sind, Folge leisten, behalte mir jedoch das Recht vor, meine freiwillige Mitwirkung jederzeit zu beenden, ohne daß mir daraus Nachteile für meine weitere Betreuung entstehen.

Ich bin zugleich damit einverstanden, daß meine im Rahmen dieser Erhebung ermittelten Daten aufgezeichnet werden. Um die Richtigkeit der Datenaufzeichnung zu überprüfen, dürfen Beauftragte der zuständigen Behörden bei der Erhebungsleiterin Einblick in meine personenbezogenen Krankheitsdaten nehmen.

Beim Umgang mit den Daten werden die Bestimmungen des Datenschutzgesetzes beachtet.

Eine Kopie dieser PatientInneninformation und Einwilligungserklärung habe ich erhalten. Das Original verbleibt bei der Erhebungsleiterin.

....
(Datum und Unterschrift der Teilnehmerin, des Teilnehmers)

....
(Datum, Name und Unterschrift der Erhebungsleiterin)

Appendix B

Quantitative Questionnaire

The following quantitative questionnaire was used in the survey. Both, the English and German version are included. It includes the Benefit Finding in Multiple Sclerosis Survey (BfiMSS)[61], the TPF[9] and the HALEMS 10.0/HAQUAMS[27].

Dear Study Participant,

This questionnaire contains a number of statements about certain conducts, thoughts, feelings and perceptions that you show more or less frequently. In each case you should state how frequently the respective conducts, thoughts, feelings and perceptions occur in you. To this effect please check “always”, “often”, “sometimes”, “never”.

In some sentences a word is skipped. This is marked with three dots. You should mentally insert the one of the four frequencies in its place that is most appropriate for you.

You need not spend much time contemplating about the answers. There are no right or wrong answers. The interest is rather on your personal point of view.

Your answers are kept strictly confidential.

Please answer all questions.

TPF

Please complete the following sentences with the words you find most appropriate describing you (always, often, sometimes or never)

	always	often	sometimes	never
1. I am…convinced, that it is very possible to like me	☐	☐	☐	☐
2. I am … lighthearted and am in a good mood.	☐	☐	☐	☐
3. I find myself … very likeable.	☐	☐	☐	☐
4. I am … perfectly happy and in total harmony with myself and my environment.	☐	☐	☐	☐
5. I am … easygoing and carefree.	☐	☐	☐	☐
6. I am … a calm and even-tempered person.	☐	☐	☐	☐
7. I am... receptive to personal critique	☐	☐	☐	☐
8. When something goes wrong, I am… convinced that it will get better sooner or later.	☐	☐	☐	☐
9. I am … proud of my body.	☐	☐	☐	☐
10. My character is … appreciated by others.	☐	☐	☐	☐
11. I have … the impression that most other people like me.	☐	☐	☐	☐
12. When something temporarily aggravates me or makes me lose my poise, then I can … cope with it faster compared to others.	☐	☐	☐	☐

	always	often	sometimes	never
13. When a person who is close to me is sad, I … notice that immediately.	☐	☐	☐	☐
14. My thoughts ... revolve around myself so much that I have difficulties being empathic with others.	☐	☐	☐	☐
15. To be helpful to others makes me ... happy	☐	☐	☐	☐.
16. I can ... empathize with other humans very well.	☐	☐	☐	☐
17. I can … express a lot of love to another human.	☐	☐	☐	☐
18. Expressing affections and tenderness is explicitly … difficult for me.	☐	☐	☐	☐
19. I ... participate intensely in the life of my friends.	☐	☐	☐	☐
20. I have … problems with accepting other peoples' weaknesses and faults.	☐	☐	☐	☐
21. I ... think about how I can make a person whom I like happy.	☐	☐	☐	☐
22. I am ... trying to be considerate to the feelings of others.	☐	☐	☐	☐
23. When other people confide their problems to me, I ... experience the urge to help them.	☐	☐	☐	☐

Quality of Life (based on Hamburg quality of life questionnaire for MS (HAQUAMS) 3.)

The following questions are related to your wellbeing since being diagnosed with MS. Please select the number from 1 to 5 that is most appropriate for you (1 - not at all, 2 - a little bit, 3 - somewhat, 4 - quite a bit, 5 - very much)

	not at all	a little bit	somewhat	quite a bit	very much
1. I feel distant from my friends and my family.	1	2	3	4	5
2. I get support from friends or neighbours.	1	2	3	4	5
3. I get support from my family.	1	2	3	4	5
4. Communication about my illness is poor with my family.	1	2	3	4	5
5. My condition impairs my relationships to other people (friends, family)	1	2	3	4	5
6. I feel separated.	1	2	3	4	5
7. I am satisfied with my sex life.	1	2	3	4	5
8. I am depressed about my condition.	1	2	3	4	5
9. I am scared because of my condition.	1	2	3	4	5
10. I can enjoy life.	1	2	3	4	5
11. I feel a sense of purpose in my life.	1	2	3	4	5
12. I am full of energy.	1	2	3	4	5
13. I am content with my quality of life.	1	2	3	4	5
14. I feel useless.	1	2	3	4	5
15. I am losing hope about the fight against my illness	1	2	3	4	5
16. How far does MS affect your ability to live a normal life?	1	2	3	4	5

(Mark 1 if MS does not affect your position in life, your job or your family. Select 5 if MS makes you completely dependent and incapable of living a normal life)

Benefit Finding in Multiple Sclerosis Scale (BFiMSS)

Sometimes people who have an illness find something positive about the experience. **Please rate how much you have experienced each item below as a result of having MS.**

		Not at all	**Somewhat**	**A great deal**
1	I have become more spiritual	1	2	3
2	My friends and family worry about me more	1	2	3
3	I have become more aware of the needs of others	1	2	3
4	I have learned to slow down	1	2	3
5	I have become more accepting of myself	1	2	3
6	I have learned to take one day at a time	1	2	3
7	I have re-evaluated my diet and physical activity	1	2	3
8	I have become closer to my family	1	2	3
9	I have experienced beneficial change in an important relationship	1	2	3
10	I have become more independent	1	2	3
11	I have learned to be more courageous	1	2	3
12	New opportunities have become available which would not have otherwise occurred	1	2	3
13	I have become more aware of, and in tune with my health	1	2	3
14	I have become more compassionate towards others	1	2	3
15	I have a better understanding of spiritual matters	1	2	3
16	I have been able to meet more people, some of whom have	1	2	3

	become good friends			
17	I have learned to relax	1	2	3
18	I have learned the importance of having a balanced life style	1	2	3
19	I have learned more about MS	1	2	3
20	I have learned how to reach out and help others	1	2	3
21	I have become more respectful of others	1	2	3
22	I have taken more control over my health	1	2	3
23	I have learned to give support and hope to others with MS	1	2	3
24	I have learned to communicate better with people	1	2	3
25	I have become more accepting of others	1	2	3
26	I have learned that everyone has a purpose in life	1	2	3
27	I have kept in better contact with my family	1	2	3
28	I have learned to be more positive	1	2	3
29	I have learned to appreciate what I have	1	2	3
30	I have established a new path for my life	1	2	3
31	I have become more aware of the love and support available from other people	1	2	3
32	I have learned to be patient	1	2	3
33	My faith has been strengthened	1	2	3
34	I have become more aware of alternative treatments	1	2	3
35	I have found new faith	1	2	3
36	I have developed new interests	1	2	3
37	I have become motivated to get more out of life	1	2	3

38	I have become more motivated to succeed	1	2	3
39	I have developed greater inner strength	1	2	3
40	I have more time to do activities I value	1	2	3
41	My friends and family have become more helpful	1	2	3
42	I have developed new relationships with supportive others	1	2	3
43	My life has become less complicated	1	2	3

Gender

female ☐

male ☐

Age _____ years old

Family Situation

☐ Single

☐ Civil Union

☐ In a relationship

☐ Married

☐ Divorced

☐ Widowed

☐ Number of own children: __________

Living Situation

☐ alone

☐ with parents

☐ with partner

Living Situation II

☐ in a city

☐ in a municipality

☐ in a village

State and Postal Code: __________

Employment Status

☐ blue-collar worker

☐ employee

☐ self-employed

☐ retired due to health reasons

☐ not working

☐ unemployed

☐ others: _____________

Job title: __________________

Amount of Employment

☐ less than 10 hours weekly

☐ Part time (______ hours weekly)

☐ Full time

Highest Completed Level of Education

☐ Middle School (Junior High School)

☐ Apprenticeship

☐ Secondary School (High School)

☐ Community College

☐ College / University

Monthly Net-income

☐ up to $ 550,--

☐ $ 551 - $ 850,--

☐ $ 851 - $ 1,150,--

☐ $ 1,151 - $ 1,500

☐ $ 1,501 - $ 1,700

☐ $1,701 - $ 2,000

☐ $ 2,001 - $ 2,300

☐ more than $ 2,300

When were you diagnosed MS? ______ years ago, in 19______

When did you recognize the first symptoms? ______ years ago, in 19_______

Liebe Reha-Besucherin, lieber Reha-Besucher,

der Fragebogen enthält eine Reihe von Aussagen über bestimmte Verhaltensweisen, Gedanken, Gefühle und Einstellungen. Bitte geben Sie jeweils an, wie häufig die entsprechenden Verhaltensweisen, Gefühle und Gedanken bei Ihnen auftreten. Zu diesem Zweck setzen Sie bitte ein Kreuz in eine der vorgegebenen Antwortkategorien.

Sie brauchen bei der Beantwortung nicht lange nachzudenken, uns interessiert vielmehr Ihre persönliche Sichtweise. Es gibt daher keine richtigen oder falschen Antworten.

Ihre Antworten werden absolut vertraulich behandelt und nur anonymisiert ausgewertet.

Beantworten Sie bitte alle Fragen.

Herzlichen Dank für Ihre Mitarbeit

MMag.ª Heidemarie Lex
Univ. Prof. Dr. Wolfgang Freidl
Institut für Sozialmedizin und Epidemiologie
Medizinische Universität Graz

Bei Fragen wenden Sie sich bitte an MMag.ª Heidemarie Lex
Tel.Nr.: 0676 68 54 008
E-mail: heidi.lex@gmail.com

TPF (copyright by Verlag für Psychologie, Dr. C. J. Hogrefe, Göttingen)

In den folgenden Sätzen ist an bestimmten Stellen ein Wort ausgelassen (durch 3 Punkte - … - gekennzeichnet). Sie können aus ***immer****,* ***oft****,* ***manchmal*** *und* ***nie*** *wählen. Bitte kreuzen Sie jene Option an, die Sie dort einfügen würden.*

	Immer	**oft**	**manchmal**	**nie**
1. Ich bin … überzeugt davon, dass man mich sehr mögen kann.	☐	☐	☐	☐
2. Ich bin … unbeschwert und gut aufgelegt.	☐	☐	☐	☐
3. Ich finde mich … sehr sympathisch.	☐	☐	☐	☐
4. Ich bin … wunschlos glücklich und im völligen Einklang mit mir und meiner Umwelt.	☐	☐	☐	☐
5. Ich bin … unbekümmert und sorglos.	☐	☐	☐	☐
6. Ich bin … ein ruhiger und ausgeglichener Mensch.	☐	☐	☐	☐
7. Ich bin … offen für Kritik an meiner Person._	☐	☐	☐	☐
8. Wenn etwas schief gelaufen ist, sage ich mir …, das wird sich mit der Zeit schon wieder einrenken.	☐	☐	☐	☐
9. Ich bin … stolz auf meinen Körper.	☐	☐	☐	☐
10. Meine Art kommt bei anderen … gut an.	☐	☐	☐	☐
11. Ich habe … das Gefühl, dass die meisten Menschen mich gerne mögen.	☐	☐	☐	☐
12. Wenn mich irgendetwas vorübergehend innerlich erregt oder aus dem Gleichgewicht gebracht hat, werde ich … schneller damit fertig als andere.	☐	☐	☐	☐
13. Wenn ein mir nahestehender Mensch bedrückt ist, bemerke ich dies … sofort._	☐	☐	☐	☐
14. Meine Gedanken kreisen … so sehr um meine eigene Person, dass es mir schwerfällt, auf andere Menschen einzugehen	☐	☐	☐	☐
15. Es macht mir … Freude, anderen behilflich zu sein.	☐	☐	☐	☐
16. Ich kann mich in andere Menschen … sehr gut hineinfühlen.	☐	☐	☐	☐
17. Ich kann einem anderen Menschen … sehr viel Liebe geben.	☐	☐	☐	☐
18. Gefühle der Zuneigung und Zärtlichkeit deutlich zu zeigen, fällt mir … schwer.	☐	☐	☐	☐

	Immer	**oft**	**manchmal**	**nie**
19. Ich nehme … regen Anteil am Leben meiner FreundInnen.	☐	☐	☐	☐
20. Die Schwächen und Fehler meiner Mitmenschen zu verzeihen fällt mir … schwer.	☐	☐	☐	☐
21. Ich mache mir … Gedanken darüber, womit ich einem Menschen, den ich gerne mag, eine Freude bereiten kann	☐	☐	☐	☐
22. Ich bemühe mich … darum, auf die Gefühle anderer Rücksicht zu nehmen.	☐	☐	☐	☐
23. Wenn andere mir ihre Probleme anvertrauen, verspüre ich … den Wunsch, Ihnen zu helfen.	☐	☐	☐	☐

2) Fragen zu Ihrer Lebensqualität (nach Lebensqualitätsfragebogen HALEMS 10.1, IniMS, UKE, Hamburg)

Die folgenden Fragen beziehen sich auf Ihr Befinden seit der Erkrankung an Multipler Sklerose: Bitte kreuzen Sie je von 1 bis 5 an, welche Antwortkategorie (gar nicht, ein wenig, mäßig, ziemlich, sehr) bei den einzelnen Aussagen am besten auf Sie zutrifft:

	gar nicht	**ein wenig**	**mäßig**	**ziemlich**	**sehr**
1. Ich fühle mich von meinen FreundInnen innerlich entfernt.	1	2	3	4	5
2. Ich erhalte Unterstützung von FreundInnen oder NachbarInnen	1	2	3	4	5
3. Ich erhalte Unterstützung von meiner Familie.	1	2	3	4	5
4. Es ist schwierig, in meiner Familie von meiner Krankheit zu sprechen.	1	2	3	4	5
5. Meine Krankheit beeinträchtigt den Kontakt zu anderen Menschen (FreundInnen, Bekannte, Familie).	1	2	3	4	5
6. Ich fühle mich ausgeschlossen.	1	2	3	4	5
7. Ich bin mit meinem Sexualleben zufrieden.	1	2	3	4	5
8. Ich bin deprimiert über meinen Gesundheitszustand.	1	2	3	4	5
9. Meine Krankheit macht mir Angst.	1	2	3	4	5
10. Ich kann mein Leben genießen.	1	2	3	4	5
11. Ich sehe einen Sinn in meinem Leben.	1	2	3	4	5
12. Ich habe Lust, etwas zu tun.	1	2	3	4	5
13. Haben Sie sich in den letzten zwei Wochen an den meisten Tagen und die meiste Zeit des Tages depremiert oder bedrückt gefühlt?	1	2	3	4	5
14. Haben Sie in den letzten zwei Wochen kein Interesse gehabt, irgendetwas zu tun oder haben Sie keine Freude an Dingen gehabt, die Ihnen sonst Spaß gemacht haben?	1	2	3	4	5
15. Ich bin derzeit mit meiner Lebensqualität zufrieden.	1	2	3	4	5
16. Wie massiv beeinflusst insgesamt die MS Ihre Fähigkeit, ein normales Leben zu führen?	1	2	3	4	5

(Eine Markierung bei 1 würde bedeuten, dass die MS keinen Einfluss auf Ihre Stellung im Leben, im Beruf, in der Familie hat. Eine Markierung bei 5 meint, dass die MS Sie völlig unfähig macht, ein normales Leben zu führen und damit völlig abhängig von Ihrer Umwelt)

3) Fragen zur Lebensentwicklungen mit MS (BfiMSS nach Dr. Kenneth I. Pakenham, School of Psychology, The University of Queensland, Australia , deutsche Übersetzung: MMag.ª Heidemarie Lex, and DI Alexander Lex)

Bitte kreuzen Sie bei den folgenden Aussagen an, inwieweit Sie die genannte Erfahrung resultierend aus Ihrer Erkrankung an Multipler Sklerose gemacht haben. (Antwortmöglichkeiten: „Überhaupt nicht“, „Ein wenig“, „Sehr viel“)

	Überhaupt nicht	**Ein wenig**	**Sehr viel**
1. Ich wurde spiritueller.	☐	☐	☐
2. FreundInnen und Familie machen sich mehr Sorgen um mich.	☐	☐	☐
3. Mir sind die Bedürfnisse anderer bewusster geworden.	☐	☐	☐
4. Ich habe gelernt, es langsamer angehen zu lassen.	☐	☐	☐
5. Ich kann mich selbst besser akzeptieren.	☐	☐	☐
6. Ich habe gelernt, einen Tag nach dem anderen zu leben.	☐	☐	☐
7. Ich habe meine Ernährung und meine körperliche Betätigung neu bewertet.	☐	☐	☐
8. Ich habe eine engere Beziehung zu meiner Familie.	☐	☐	☐
9. Ich habe vorteilhafte Veränderungen in wichtigen persönlichen Beziehungen erfahren.	☐	☐	☐
10. Ich bin unabhängiger.	☐	☐	☐
11.Ich bin mutiger.	☐	☐	☐
12. Neue Möglichkeiten haben sich aufgetan, die sich sonst nicht ergeben hätten.	☐	☐	☐
13. Ich wurde mir meiner Gesundheit bewusster und bin mit ihr mehr im Einklang.	☐	☐	☐
14. Ich bin anderen gegenüber mitfühlender.	☐	☐	☐
15 Ich habe ein besseres Verständnis für spirituelle Belange.	☐	☐	☐
16. Ich habe mehr neue Menschen kennengelernt, wovon einige gute Freunde/Freundinnen wurden.	☐	☐	☐
17. Ich habe gelernt, mich zu entspannen.	☐	☐	☐
18. Ich habe die Bedeutung eines ausgeglichenen Lebensstils kennengelernt.	☐	☐	☐
19. Ich habe mehr über MS gelernt.	☐	☐	☐

	Überhaupt nicht	**Ein wenig**	**Sehr viel**
20. Ich habe gelernt, anderen meine Hilfe anzubieten.	☐	☐	☐
21. Ich wurde anderen gegenüber respektvoller.	☐	☐	☐
22. Ich habe mehr Verantwortung für meine Gesundheit übernommen.	☐	☐	☐
23. Ich habe gelernt, andere Menschen mit MS Unterstützung und Hoffnung zu geben.	☐	☐	☐
24. Ich habe gelernt, mit anderen besser zu kommunizieren.	☐	☐	☐
25. Es fällt mir leichter, andere so zu akzeptieren, wie sie sind.	☐	☐	☐
26. Ich habe gelernt, dass jede/r eine Bestimmung im Leben hat.	☐	☐	☐
27. Ich habe mehr Kontakt zu meiner Familie.	☐	☐	☐
28. Ich habe gelernt, das Leben positiver zu sehen.	☐	☐	☐
29. Ich habe gelernt, das zu schätzen, was ich habe.	☐	☐	☐
30. Ich habe einen neuen Weg in meinem Leben gefunden.	☐	☐	☐
31. Mir ist die Liebe und Unterstützung anderer bewusster geworden.	☐	☐	☐
32. Ich habe gelernt, geduldig zu sein.	☐	☐	☐
33. Mein Glaube ist stärker geworden.	☐	☐	☐
34. Ich bin offener für alternative Behandlungsmöglichkeiten geworden.	☐	☐	☐
35. Ich habe Glauben gefunden.	☐	☐	☐
36. Ich habe neue Interessen entwickelt.	☐	☐	☐
37. Ich bin motivierter, mehr aus dem Leben herauszuholen.	☐	☐	☐
38. Ich bin motivierter, erfolgreich zu sein.	☐	☐	☐
39. Ich habe größere innere Stärke entwickelt.	☐	☐	☐
40. Ich habe mehr Zeit für Aktivitäten, die mir wichtig sind.	☐	☐	☐
41. Meine FreundInnen und meine Familie sind hilfreicher geworden.	☐	☐	☐
42. Ich habe neue Beziehungen zu unterstützenden Menschen aufgebaut.	☐	☐	☐
43. Mein Leben ist weniger kompliziert.	☐	☐	☐

4) Soziodemographische Daten

Geschlecht

weiblich ☐
männlich ☐

Alter: _____ Jahre

Familienstand

☐ Verheiratet
☐ In einer Lebensgemeinschaft
☐ In einer Beziehung
☐ Nicht in einer Beziehung/ledig
☐ Geschieden
☐ Verwitwet
Anzahl eigener Kinder: ___________

Wohnsituation

☐ allein lebend
☐ bei Eltern lebend
☐ mit PartnerIn lebend

☐ in Stadt lebend
☐ in Gemeinde lebend
☐ in Dorf lebend

Bundesland und Bezirk: _________________

Berufstätigkeit

☐ ArbeiterIn
☐ AngestellteR
☐ SelbständigeR
☐ In Pension
☐ Nicht Berufstätig
☐ Arbeitslos
☐ Sonstiges _______________

Im Falle einer Berufstätigkeit:

Berufsbezeichnung: ____________________

Stundenausmaß der Beschäftigung

☐ Geringfügig
☐ Teilzeit (____ Stunden)
☐ Vollzeit

Höchste abgeschlossene Ausbildung

☐ Hauptschule
☐ Lehre
☐ Fachschule
☐ Matura
☐ College nach Matura
☐ Universität/Fachhochschule

Ihr Netto-Einkommen pro Monat

☐ bis € 500,--
☐ € 501,-- - € 1.000,--
☐ € 1001,-- bis € 1.300,--
☐ € 1.301,-- bis 1.500,--
☐ € 1.501,-- bis € 1.800,--
☐ € 1.801 bis € 2.000,--
☐ mehr als € 2.000,--

Wann wurde bei Ihnen Multiple Sklerose diagnostiziert?: ______ / vor ______ Jahren

Wann machten sich die ersten Symptome bemerkbar? : ______ / vor ______ Jahren

Appendix C

Qualitative Interview Guidelines

The questions included on the following pages were used to structure the qualitative part of the interview. Both, the English and German version are included.

Qualitative Interview

Self-perception

1. What qualities would you use to describe yourself?
2. In what respects would you wish to be different than you are?
3. Which three body areas are most affected by your illness?
4. How do you cope with the realization that you are ill? (coping with illness)

Living with Multiple Sclerosis

5. How would you rate yourself with the illness, independent or having to rely on others or somewhere in-between?
6. Which (negative) life events were there in your life before your illness?
7. How do you cope with stress?

Health Literacy

8. Accessing the healthcare system: Which support services of the healthcare system did you use?
9. In the last few years, did you have negative experiences with medical personnell that compromised your trust in the system?
10. How well are your caregivers organized / coordinated with each other?
11. How did you get your knowledge about MS?
12. What would you wish for, that has not been extended to you yet through the healthcare system?
13. What do you think how much does your contribution concerning your therapy influence

your disease progression? In your opinion, does your own therapy contribution affects the progression of your illness?

14. Are you already participating in educational courses for patients (if yes, how often) or would you like to participate in them? If not, why?
15. What are the decisive criteria for proper care of your illnesss? What do you need as a patient to consider your care as good?

Subjective perception of the illness

16. What explanation do you have for what caused your MS?
17. Most recent relapse – preliminary explanations for it?

Health related questions

18. Please rate your health on a scale from 0 (very bad) to 10 (very good).

Questions relating to quality of Life

19. What changes in your life have you perceived since your diagnosis?
20. What changes in your life have you perceived since starting treatment?
21. Please describe your most significant experience resulting from MS.
    What experiences have you had as a person with MS that are most notable?
22. What are your hobbies?
23. How do you spend your free time?

Social Networks and Bonding

24. Please describe your relationship to your mother in three sentences.

25. Who helps you when you are at your wits’ end?
26. Do you have siblings? On which birth position were you? How old was your mother when you were born?

Qualitatives Interview

Selbstbild

1. Wie würden Sie sich selbst beschreiben, mit welchen Eigenschaften?
2. In welchen Punkten wären Sie gern anders als Sie sind?
3. Welche drei körperlichen Bereiche sind bei Ihnen am meisten von der Krankheit betroffen?
4. Wie geht es Ihnen damit sich einzugestehen, dass Sie krank sind? (Krankheitsbewältigung)

Leben mit Multipler Sklerose

5. Selbstbestimmtes Leben – fremdbestimmtes Leben mit MS – wie/wo würden Sie sich einordnen?
6. Welche (Negative) Life Events – Lebensereignisse, gab es vor Ihrer Erkrankung in Ihrem Leben? - Markante Erfahrungen, verändernde Lebensereignisse
7. Wie gehen Sie mit Stress um?

Health Literacy

8. Inanspruchnahme des Gesundheitswesens: Welche unterstützenden Angebote des Gesundheitssystems haben Sie angenommen?
9. Gab es in den letzten Jahren negative Erfahrungen mit medizinischem Personal, die Ihr Vertrauen in dieses beeinträchtigt haben?
10. Wie funktioniert die Organisation/Koordination der Sie Behandelten unter/miteinander?
11. Woher haben Sie Ihr Wissen über MS?
12. Was würden Sie sich wünschen, was bisher noch nicht angeboten wurde?
13. Was meinen Sie, trägt Ihre persönliche Therapiekooperation zu Ihrem Krankheitsverlauf bei?
14. Absolvierten Sie bereits PatientInnenschulungen (wenn ja, wie oft) bzw. hätten Sie gern welche?
15. Welche Kriterien sind für Sie für eine gute Versorgung mit der Erkrankung ausschlaggebend? Was brauchen Sie als PatientIn, damit Sie es als gute Versorgung erachten würden?

Subjektives Krankheitsmodell

16. Wie erklären Sie sich selbst, dass Sie an MS erkrankt sind?
17. Letzter Schub – Erklärungsansätze dafür?

Gesundheitsfragen

18. Eigene Einschätzung des Gesundheitszustands auf Skala von 0 (sehr schlecht) bis 10 (sehr gut)

Fragen zur Lebensqualität

19. Welche Veränderungen in Ihrem Leben haben Sie seit der Diagnose wahrgenommen?
20. Welche Veränderungen in Ihrem Leben haben Sie seit Behandlungsbeginn wahrgenommen?
21. Welche Erfahrungen zählen zu den markantesten, die Sie als Person mit MS gemacht haben?
22. Welche Hobbies haben Sie?
23. Wie verbringen Sie Ihre Freizeit?

Soziale Netzwerke und Bonding

24. Beschreiben Sie bitte in drei Sätzen Ihr Verhältnis zu Ihrer Mutter
25. Wer hilft Ihnen, wenn Sie nicht mehr weiter wissen?
26. Haben Sie Geschwister? Wie vielte/r sind Sie in Geschwisterreihenfolge? Wie alt war Ihre Mutter bei Ihrer Geburt?