Social-emotional aspects of quality of life in multiple sclerosis

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ABSTRACT

Multiple sclerosis (MS) is an inflammatory auto-immune disease of the central nervous system. It leads to many impairments including physical, cognitive, psychological, and social challenges. Our study examined gender and cultural associations with quality of life (QoL), personal characteristics, and benefits from having MS among those with MS. The study was conducted in Austria and the United States. The sample included 128 participants, 64 in each country, of whom 78 were women and 50 were men aged between 20 and 57 years. We used standard statistical tests, including analyses of covariance (ANCOVA) and partial correlations for the analysis of quantitative data. For the qualitative part of the survey we used semi-structured interviews, which we transcribed and coded to identify categories in the answers for qualitative analyses. Austrian participants with MS perceived a higher social-emotional QoL in comparison to American participants. American participants expressed a higher self-esteem in comparison to Austrian participants. Men reported a lower ability to express love than women. Independent of sex/gender and nationality, participants reported benefits through the disease, especially with regard to improved compassion, mindfulness, improved family relations and lifestyle gains. The qualitative interviews revealed additional gender differences for coping with the illness; and in experiences, expectations, and challenges related to MS. These insights can be used to develop targeted psychological and social support interventions aimed toward improving social-emotional QoL for persons with MS.

Introduction

Persons with MS often experience a diminished quality of life (QoL) due to the progression and symptoms of the illness (Campbell et al., 2014). There are several themes that have arisen in studies evaluating QoL among individuals with MS, including leaving or reducing paid employment (Irvine, Davidson, Hoy, & Lowe-Strong, 2009), changes in social relationships (Charmaz, 1983), and altered perceptions of self (Boeije, Duijnste, Grypdonck, & Pool, 2002; Kralik, Koch, & Eastwood, 2003).
Women are affected with MS approximately twice as often as men (Alcalde-Cabero, Almazán-Isla, García-Merino, de Sá, & de Pedro-Cuesta, 2013; Stüve & Oksenberg, 2006), and various studies have identified genetic and hormonal sex and gender differences in MS (Garcia-Montojo et al., 2013; Tillack et al., 2013). Most studies of MS have been conducted with women only, or have lacked the power to make gender comparisons (Irvine et al., 2009; Kralik et al., 2003; Reynolds & Prior, 2003). Themes that have arisen among studies of only women have revealed topics such as missing being able to wear high heels, potentially indicating a sense of lost femininity (Irvine et al., 2009).

Coping is an essential mechanism for accepting and living with a chronic disease, such as MS. As Ahadi and colleagues (Ahadi et al., 2014) observed, individuals with MS use a variety of coping strategies in response to stressors, including problem-focused strategies, social support, planful problem solving, distancing, escape and avoidance, and self-control, but are less likely to use confrontation-based coping, relative to healthy comparisons. Stress management (Moss-Morris et al., 2009; Wagner et al., 2012) and self-management (Audulv, 2013; Corbin, Strauss, & Hildenbrand, 2004; Sauter, Zebenholzer, Hisakawa, Zeitlhofer, & Vass, 2008) strategies are important in response to constant adaptations to newly appearing health issues.

Figure 1 illustrates positive coping — self-management and stress-management strategies recommended for dealing with MS and how QoL can be improved.

One study has evaluated gender differences in stressors experienced and methods of coping with stressors (Matud, 2004). Women reported emotional coping styles more often and indicated less detached coping styles than men, while men described more emotional inhibition than women. The typical female coping style is more emotion-focused, whereas the male coping style is more detached.

Oriented on the latest literature we sought to draw a picture of MS as a whole and look beyond the mostly negative aspects of MS. We use the term social-emotional QoL, as we were primarily interested in psychological, emotional and social aspects of QoL among those with MS. For this reason, we used only aspects of questionnaires that relate to emotional and social QoL and personal characteristics. To extend knowledge about gender differences in QoL in MS, the first aim of the current study was to investigate gender differences in social-emotional QoL, self-esteem, the ability to express love and coping

![Figure 1](image.png)

**Figure 1.** Positive coping – self-management and stress-management strategies.
strategies for MS. Second, given the dearth of information about how culture and geographic location might impact QoL in MS, we also sought to explore QoL in those with MS living in Austria and the United States. We expected national differences in social-emotional qol, self-esteem and the ability to express love.

**Material and methods**

**Participants**

Our study was conducted in Austria and the United States. The sample included 128 participants, 64 in each country, of whom 78 were women and 50 were men aged 18 to 57 years. In Austria, the sample was drawn from an inpatient neuro-rehabilitation clinic near Graz (Klinik Judendorf Strassengel) in Styria, which has dedicated physical therapy facilities for MS inpatients. The survey in the U.S.A. was conducted among outpatients at the Beth Israel Deaconess Medical Center (BIDMC) in Boston, MA, at the Multiple Sclerosis Center. Table 1 displays the key sample demographics, the distribution of participants in terms of gender, age and MS related characteristics.

Inclusion criteria for participation was *clinically definite MS diagnosis* (including all MS types such as relapsing remitting, primary progressive or secondary progressive). Additionally, *a strongly unbalanced gender ratio was avoided* and only participants with the *cognitive ability to complete the questionnaire and participate in the qualitative interview*, were included.

**Procedure**

In both countries, the respective institutional review board approved the study (Ethics Commission of the Medical University of Graz and the IRB of the BIDMC in Boston). A written study information sheet as well as an oral explanation was given to the participants. Participants were informed that participation was voluntary, and their refusal to participate had no consequences for their continuing treatment or the relationship with their doctors. Participants were asked to read the informed consent form, ask clarifying questions, and provide their signature to express consent. To keep the survey situations as similar as possible and to exclude an interviewer bias, all interviews were conducted by the same person (HL) who speaks both languages fluently.

| Table 1. Key sample demographics. | Austria | US |
|-----------------------------------|--------|----|
| Participants                       | 64     | 64 |
| Women                             | 39     | 39 |
| Men                               | 25     | 25 |
| Mean age (18–57)                  | 44.08 (SD = 8) | 41.63 (SD = 8.64) |
| Mean EDSS (0: no disability to 10: death) | 4.54 (SD = 2.22) | 2.88 (SD = 2.30) |
| Mean MS duration (years)          | 12.1 (SD = 7) | 9.33 (SD = 7.4) |
| Educational level N total (percentage) |        |    |
| No completed secondary education  | 5 (7.9%) | 3 (4.7) |
| Completed secondary education     | 48 (76.2%) | 20 (31.3%) |
| Completed higher education/university | 10 (15.9%) | 41 (64.1) |
**Measures**

In quantitative questionnaires (see Table 2) and qualitative interviews (see Supplementary Materials), we asked questions about emotional and social aspects of QoL with MS, including self-esteem, the ability to express love, experiences with and changes since being diagnosed with MS. We selected Austria and the United States as study sites because in both regions MS is prevalent (Austria 98.5 per 100,000 population (Baumhackl, 2011), U.S., 90 per 100,000 population (Harsh & Fox, 2000–2015) although they differ in language, social security systems, and healthcare provisions (i.e. Austria has a national healthcare system). The survey material was carefully translated and back-translated by independent parties, to guarantee consistent comparisons and interpretations of the results for the two subsamples.

The first part of the questionnaire was composed of two subscales of the personality inventory TPF – Trierer Persönlichkeitsfragebogen (Becker, 1989b), specifically the sense of self-esteem scale and the ability to love scale. The TPF measures two aspects of personality: mental health and behavior control. The two scales used were translated to English. The questionnaire originally is in German, for age 17–80 years. The TPF has been primarily a clinical, rather than research measure, and we selected the two subscales that measure mental health (1989a).

The second part of the questionnaire included parts of the questionnaire HAQUAMS -Hamburger QoL in Multiple Sclerosis Scale (Gold et al., 2001). The subscales social function, mood, and handicap were used in the questionnaire. The third part of the questionnaire was the BFIMSS -Benefit Finding in Multiple Sclerosis Scale (Pakenham & Cox, 2009). At the end of the quantitative questionnaire we asked questions eliciting sociodemographic data (see Table 2). We used the entire BFIMSS, though for stronger reliability we excluded two questions from further calculations (see Supplementary Materials for details). We realize that using subscales originally designed to be used as part of a larger scale can result in reduced reliability. We calculated Crombach’s Alpha for all subscales. Reliability of all scales was moderate to good >.6 (For example self-esteem scale .86., ability to love scale .77, social-emotional qol scale .84).

The quantitative part of the study was followed by a one-on-one qualitative interview, where 26 open-ended questions were asked. We used content analysis to analyze qualitative data (Backman & Hentinen, 2001; Elo & Kyngäs, 2008), which is recommended when there are no previous studies dealing with the topic or when knowledge is fragmented. The questions asked dealt with the topics self-perception, living with MS, health literacy, subjective perception of the illness, health-related questions, questions related to QoL, and

| Table 2. Overview of the quantitative instruments used. |
|--------------------------------------------------------|
| Questionnaires                                       | Subscales used                                      | # questions |
| TPF-Trierer Persönlichkeitsfragebogen (Becker, 1989b) | Sense of self-esteem, ability to love                | 23          |
| HALEMS/HAQUAMS (Hamburger quality of life in MS) (Gold et al., 2001) | Social function, mood, handicap, satisfaction with sex life | 16          |
| BFIMSS – benefit finding in multiple sclerosis scale (Pakenham & Cox, 2009) | Compassion, spiritual growth, mindfulness, new opportunities, life style gains, family relations growth, personal growth | 43          |
| Sociodemographic data                                 | Gender, age, living situation, …                     | 14          |
social support (see Supplementary Materials for details). We chose qualitative interviews to give participants the opportunity to name specific views and interpretations that may not be evident from questionnaires. The questions were selected based on current literature about challenges of living with chronic disease in general and MS in particular (Fortin et al., 2013). We used gender-neutral language.

**Data analysis**

To analyze the quantitative data, we used ANCOVAs for identifying gender and national differences (dependent variables: QoL scale, self-esteem and ability to love scales, benefit finding scale) and partial correlations to identify similarities in the sample. We controlled for possibly confounding variables including age, EDSS (Expanded Disability Status scale), MS duration, and educational level as covariates in the quantitative data analyses, as the subsamples differ (see Table 1). Missing data was replaced by using means of the specific scales of the subsample.

For the qualitative interview, we transcribed the answers to identify underlying categories. Specifically, similar answer patterns were put together in one category. We summarized answers dealing with similar topics in a category and counted the number of answers in each category.

We analyzed qualitative data separately for Austria and U.S.A. Controlling for confounding variables was not possible in the qualitative analyses which could bias conclusions on differences of these countries. (see Supplementary Material for interview details).

**Quantitative results**

**Gender differences**

Concerning personal characteristics, men expressed a lower *ability to love* compared to women, who reported greater ease in expressing their feelings ($F(1,118) = 12.74, p < .01$; women $M = 3.33$, men $M = 3.09$).

**Nationality differences**

Concerning personal characteristics, Austrians show significantly lower self-esteem than U.S. participants ($F(1,118) = 4.94, p < .05$) (see Table 3). There are statistical tendencies in differences regarding social-emotional QoL in nationality ($F(1,118) = 3.76, p = .06$),

| Table 3. Social-emotional QoL and Self-esteem in Austria and the United States. |
|---------------------------------------------------------------|
| **Scales**       | **AUSTRIA**               | **US**                 |
| Social-emotional QoL | **Mean** 2.1671  0.69448 | **Mean** 2.4111  0.61937 |
| Self-esteem      | **Mean** 2.67  0.06 | **Mean** 2.88  0.06 |

*Low mean values on the scale “social-emotional QoL” describe a high social-emotional qol, high mean values a low social-emotional qol (scale 1–5). Low mean values on the scale “self-esteem” describe a low self-esteem, high mean values a high self-esteem (scale 1–4).
with Austrians describing a higher social-emotional QoL in comparison to Americans (see Table 3).

**Similarities among the two sample sites**

In general, persons with high self-esteem also tended to show a high social-emotional QoL (see Table 4). Those receiving social support were more likely to report improved mindfulness and family relations growth since having MS, and persons receiving social support also reported a high self-esteem and a high ability to express love (see Table 4).

Participants found benefits in having MS especially regarding 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 ($M = 2.03, SD = 0.04$). Mean values ($M > 2$) describe improvements on these subscales since having MS (rating scale: $1 = \text{not at all}$, $2 = \text{somewhat}$, $3 = \text{a great deal}$).

**Qualitative results**

We present the qualitative data separately for Austria and the U.S. Statistical gender calculation of the coping strategies showed no significant differences, but an obvious tendency in gender differences can be observed in the figures.

**Gender similarities and differences in Austria**

As can be seen in Figure 2, in Austria more women than men pointed out ambivalent, resigned acceptance as a strategy for coping with MS (women AT 32%, men AT 16%). Acceptance in general was pointed out by more men than women (women AT 62%, men AT 80%). The categories identified in the interviews represent all responses from all participants.

**Gender similarities and differences in the US**

More men than women in the U.S. (women U.S. 5%, men U.S. 20%) pointed out denial as a coping strategy for MS (Figure 3). Additionally, more men than women pointed out ambivalence, resigned acceptance (women U.S. 15%; men U.S. 28%) (quote:

| Table 4. Partial Correlation of Self-esteem with Social-emotional QoL and partial correlations of Social Support with Self-esteem, Ability to Love, Mindfulness, Family Relations Growth. |
|-------------------------------------------------------------|
| Correlation self-esteem with … Correlation Significance     |
| … Social-emotional QoL *                                   −0.59 0.00 |
| Correlations Social Support with …                         |
| … Self-esteem                                              0.32 0.00 |
| … Ability to love                                           0.20 0.03 |
| … Mindfulness (BFIMSS scale)                               0.18 0.05 |
| … Family Relat. Growth (BFIMSS scale)                      0.36 0.00 |

Note: For all correlations $Df = 118$.

*A high social-emotional QoL is described by low values. In this case, what the negative correlation expresses is that high QoL goes along with a high self-esteem and a low QoL goes along with a low self-esteem.
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 through when probably sometimes I should step back. 

(U.S. female), as a coping strategy for MS. More women in comparison to men pointed out acceptance (women U.S. 54%, men U.S. 40%) and being active (women U.S. 31%, men U.S. 28%) (see Supplementary Material for more quotes).

The categories identified in the interviews represent all responses from all participants. For both sample sites, stress was mentioned frequently as a perceived cause for worsening symptoms of MS or even causing MS. Furthermore, negative experience with medical personnel was reported in both sample sites (see Supplementary Materials for details).

**Discussion**

We found that persons with MS in Austria reported a higher social-emotional QoL in comparison to U.S. participants, while persons from the U.S. expressed a higher self-esteem than Austrian participants. Women described a higher ability to express love than men. Independent of sex/gender and nationality, participants reported benefits through the disease, especially with regard to compassion, mindfulness, improved family relations, lifestyle gains and personal growth. The qualitative interviews further supported gender differences in coping strategies for MS.
QoL and personalized psychological interventions

Oriented on our study results we suggest developing personalized interventions for those with MS that empower self-esteem. Maintaining a high social-emotional QoL should be a goal for those with MS and their social environment, as also shown by various other studies (Boeije et al., 2002; Charmaz, 1983; Grech et al., 2016; Irvine et al., 2009; Kralik et al., 2003; Madan & Pakenham, 2014; Reynolds & Prior, 2003; Rintell, Frankel, Minden, & Glanz, 2012; Strober, 2016). It appears beneficial to offer personalized interventions oriented toward unique needs of women and men to improve their QoL.

A positive relationship between psychological interventions and physiological symptoms of MS was identified (Pagnini, Bosma, Phillips, & Langer, 2014). Especially cognitive behavioral therapy (CBT) may be helpful for adjusting, and coping with, MS, improving sleep quality and reducing stress (Abbasi, Alimohammadi, & Pahlavanzadeh, 2016; Moss-Morris et al., 2013; Thomas, Thomas, Hillier, Galvin, & Baker, 2006). Abbasi et al. (2016) identified the following CBT interventions as effective to improving sleep quality in persons with MS:

- Muscle relaxation exercises
- ABCD model (Healthypsych, 2014)
- Identifying cognitive faults and negative automatic thoughts
- Strategies to cope with negative thoughts
- Strategies to cope with stress
- Method of thought experimenting (Kleeberg, 2015)

These CBT interventions should be used for supporting MS patients in the future.

Working with those with MS on adequate coping strategies to improve their QoL might be helpful. Accepting MS and redefining boundaries in daily life as coping strategies turned out to be very important for those with MS, in our survey as well as in previous work (Hellige, 2002; Reynolds & Prior, 2003).

Additionally, future interventions should focus on bringing to awareness the positive aspects of MS, as our survey identified that those with MS found benefits in their lives while living with MS. Mindfulness empowers the ability to slow down and observe. It supports improving affect regulation (Muñoz San José et al., 2016). Interventions focusing on compassion and mindfulness could be very constructive.

Stress was mentioned frequently as a cause for worsening symptoms of MS or even causing MS (see Supplementary Materials for details). Psychoeducational courses on symptom- and stress-management (Dennison & Moss-Morris, 2010; Madan & Pakenham, 2014; Matud, 2004; Mund & Mitte, 2012) and ways to self-manage life with MS would be beneficial. Self-management instruments (Audulv, 2013; Corbin et al., 2004; Matud, 2004; Sauter et al., 2008; Wagner et al., 2012) should be offered to support chronically ill. They could be developed in the context of managing medication, coping with particularly bad episodes of MS, exercise, household activities, leisure time, work, lifestyle (such as nutrition), stress, emotions, identity, and fatigue. Recent investigations indicate that psychotherapeutic interventions for stress management, such as mindfulness-based interventions, could improve QoL, depression, anxiety, and fatigue in MS patients (Muñoz San José et al., 2016).

Oriented on our study results, working on personal characteristics, ways to improve self-esteem, increasing sociability, and developing ways to express love towards others would be constructive towards living and organizing a life with MS. Personalized interventions tailored to the patient's sex/gender would support especially men in finding ways to express love and be more social (see Supplementary Materials for details). Perceived self-efficacy is important for symptom self-management in chronic disease (Hoffman, 2013) and should
be enhanced. Kim and Youn (2015) showed significant improvements in chronic ill elderly Koreans when participating in the chronic disease self-management program.

Furthermore, negative experience with medical personnel was reported (see Supplementary Materials for details). Focusing on communication with medical personnel for future interventions seems to be fundamental for both sides, for those with MS and for their medical personnel.

**Social support**

In our study, receiving social support is closely connected to high self-esteem, an ability to express love and being mindful. Charmaz (1983) found that in the course of the illness, the 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 that bolsters self-worth. Therefore, it seems beneficial for future interventions to focus on ways to improve social support and maintain social relationships.

Those with MS pointed out partners and spouses as the most frequent sources of social support, followed by friends and parents (see Supplementary Materials for details). As these social support sources have to deal with challenges in their lives through MS in the family also (Qualls & Williams, 2013) support groups targeted at MS caregivers would be beneficial (National Multiple Sclerosis Society, 2015)

**Limitations**

Since our study was conducted in two languages, the survey questions and responses had to be translated, which could result in biases in the results. To counteract this as much as possible, the surveys were carefully translated and back-translated by independent parties to check for consistent interpretations. Another potential source of bias is the recruitment modality (inpatients vs. outpatients), which differed between the two legs of the survey for practical reasons. This might have potential consequences on study findings for comparing two different samples. As a consequence, the two samples differ in age, their disease progression, their MS duration and their educational level.

Although we controlled for these variables by using them as covariates in all quantitative analyses, we were unable to control for these variables in the qualitative analysis, and we thus analyzed separately (without making direct comparisons between the samples). For future research projects, we recommend using our identified coping strategies and let them be evaluated quantitatively by persons with MS. We recommend a bigger sample size including as many women as men.

We used portions of three questionnaires, which threatens the psychometric qualities of those instruments. Thus, the partial instruments may not be reliable and valid measures of the study’s variables. (see Supplementary Materials, which questions of the BFIMSS had to be excluded for further calculations).

**Conclusion**

We identified national differences in social-emotional QoL as well as self-esteem of those with MS, and general differences in found benefits since having MS. We found that
social-emotional QoL is equivalent for both women and men with MS. This can inform the development of psychological and social interventions for improving the social-emotional QoL of those with MS, independent of sex/gender. At the same time, we found that it is easier for women than men to express love towards others. Women and men also showed differences in their coping strategies for dealing with MS in Austria as well as in the U.S. Future interventions can be oriented toward sex/gender and national differences for improving social and emotional QoL in those with MS. Learning from each other may expand individuals’ perception of living with MS.

**Explanations of abbreviations used**

- ANCOVA: Analysis of Covariance
- AT: Austria
- BFIMSS: Benefit finding
- BFiMSS: Benefit Finding in Multiple Sclerosis Scale
- BIDMC: Beth Israel Deaconess Medical Center Harvard Teaching Hospital, Boston
- EDSS: Expanded Disability Status Scale
- HALEMS/HAQUAMS: Hamburger Quality of Life in MS Questionnaire
- HL: Heidemarie Lex
- IRB: Institutional Review Board
- MS: Multiple Sclerosis
- QoL: quality of life
- Social-emotional qol: social-emotional quality of life
- Tpf: Trierer Persoenlichkeitsfragebogen
- U.S.: United States

**Acknowledgement**

We would like to thank Dr Alexander Lex for feedback and comments on this manuscript, as well as Dr Peter Griesshofer, Dr Revere Kinkel, and Dr Marion Stein, for local support at the clinics.

**Disclosure statement**

No potential conflict of interest was reported by the authors.

**Funding**

This work was funded by the Austrian Agency for International Cooperation in Education and Research and OeAD-GmbH through its Marietta Blau scholarship.

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