



## Quality of Life and Burden in caregivers of Multiple Sclerosis patients

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### Abstract

Multiple sclerosis (MS) is one of the most disabling disorders of the central nervous system. Caregivers of individuals with MS may experience unique caregiver strain due to the age at onset and progressive nature of the disease. Additionally, because MS is more prevalent in women, men often become spousal caregivers. This places women in the position of being care recipients rather than caregivers. Some results also supported hypothesis that female caregivers reported a higher need for emotional support than male caregivers. As with female caregivers, decreased emotional support predicted poorer QoL among male caregivers.

Caring for a MS patient may negatively impact several objective and subjective aspects of caregiver's life, such as physical and emotional health, morale, work life, finances, social mobility, interpersonal relationships and sexual life. In studies assessing the psychological consequences of care a higher level of anxiety and depression in caregivers than in the general population has been reported. Caregivers who experience burden are more likely to have a higher risk of depression and a lower quality of life. Early recognition of caregiver burden is important in determining appropriate interventions.

In this review report the current state of knowledge about the QoL of MS caregivers as well the burden of MS caregivers has been described.

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## INTRODUCTION

Multiple sclerosis (MS), the most common disabling neurologic disease of young people, afflicts millions of people all over the world. The symptoms of MS result from recurrent attacks of inflammation in the central nervous system, which probably occur through an autoimmune mechanism. MS favors women over men by a ratio of nearly 2 to 1, and it strikes most often between the ages of 20 and 40. Caucasians are especially vulnerable, particularly those of northern European extraction, and there is a geographic preference for people living in northern latitudes.

MS can cause a variety of symptoms, including changes in sensation, visual problems, muscle weakness, depression, difficulties with coordination and speech, severe fatigue, cognitive impairment, problems with balance, overheating, and pain. MS will cause impaired mobility and disability in more severe cases. Multiple sclerosis may take several different forms, with new symptoms occurring either in discrete attacks or slowly accruing over time. Between attacks, symptoms may resolve completely, but permanent neurologic problems often persist, especially as the disease advances. MS currently does not have a cure, though several treatments are available that may slow the appearance of new symptoms.

Individuals with progressive subtypes of MS, particularly the primary progressive subtype, have a more rapid decline in function. In the primary progressive subtype, supportive equipment (such as a wheelchair or standing frame) is often needed after six to seven years. However, when the initial disease course is the relapsing-remitting subtype, the average time until such equipment is needed is twenty years. This means that many individuals with MS will never need a wheelchair. There is also more cognitive impairment in the progressive forms than in the relapsing-remitting MS.

The earlier in life MS occurs, the slower disability progresses. Individuals who are older than fifty when diagnosed are more likely to experience a chronic progressive course, with more rapid progression of disability. Those diagnosed before age 35 have the best prognosis. Females generally have a better prognosis than males. However their Patient-Reported Outcome (shortly PRO) is lower than in men. Women more often fall in depression and more often feel fatigue, they also more often suffer from bladder dysfunction.

MS causes decreasing of Quality of Life (QoL). In this review report the current state of knowledge about the QoL of MS caregivers as well the burden of MS caregivers has been described.

## CAREGIVERS QUALITY OF LIFE OF MS PATIENTS

Multiple sclerosis (MS) causes reduced quality of life of patients and those caring for them. While many generic and specific questionnaires were developed to

assess quality of life in patients with MS, including general fatigue, the lack of a questionnaire assessing quality of life of caregivers could be observed. In a short review paper Opara et al. (2012) presented the most popular questionnaires measuring burden and quality of life of MS people caregivers. Ucelli stated in 2014 that MS has a significant impact on families, influencing their wellbeing and quality of life, often creating psychological stress in each family member as well as on family functioning in general. Common themes include the impact of the emotional state of the person with MS on family members, the role of the healthy parent on how children cope, the effect of a lack of information about MS, communication within the family and with healthcare professionals, and the importance of assessing and treating families as a dynamic unit in order to assure comprehensive intervention plans.

Caring for a patient may have an impact on the objective and subjective aspects of a guardian, such as physical and emotional health, morale, job, finances, social activity, relationships and sex life. In studies assessing the psychological consequences of care a higher level of anxiety and depression in caregivers than in the general population has been reported. Caregivers who experience burden are more likely to have a higher risk of depression and a lower quality of life. Early recognition of caregiver burden is important in determining appropriate interventions (Buhse 2008).

Aronson (1997) conducted a large survey of persons with MS and their caregivers in Ontario using self-completed mailed questionnaires. The objectives included describing satisfaction with QOL and determining relationships between QOL as a whole and several other factors, such as demographic characteristics and measures of physical disability. Response rates were 83% for those with MS and 72% for their caregivers. Based on 697 respondents with MS, mean age was 48 years, 70% were women, and 75% were married. While 24% experienced no mobility restrictions, the majority required some type of aid or a wheelchair for getting around. Health received the lowest satisfaction rating among the six components of QOL, while finances received a relatively low satisfaction rating from the 345 caregivers. Less satisfaction with several QOL components was evident for those with MS compared with the disabled in the Canadian general population, and for caregivers compared with the able-bodied general population. Poorer QOL as a whole among those with MS was associated with unemployment, MS symptoms of moderate or worse, fatigue, mobility limitations on stairs, a disease course other than stable, and was most strongly related to interference by MS in social activities. Among caregivers, poorer QOL as a whole was associated with being a spouse, longer duration of caregiving, moderate or worse MS symptoms in the care recipient, and most strongly related to a care recipient's current MS disease course of other than stable. The author stated that through an

understanding of the satisfaction with QoL of persons with MS and caregivers, and the relationships with other important factors, autonomy and home care may be supported and prolonged, while preventing unnecessary institutionalization.

Jaracz et al. (2010) evaluated 210 MS patients (150 women) aged between 21 and 59 years. They stated that MS influences QoL but to a greater extent in the physical than the psychological domain. The role of social support measured by Social Provisions Scale (SPS) in QoL is generally positive but its protective function may be weakened when interacting with other factors. Depression is the main predictor of QoL when adjusted for other factors. Thus, treatment of mood disturbances might significantly improve QoL in MS patients.

In Patti's et al. report (2007) 445 Italian patients with definite MS and 445 of their caregivers were required to complete the 36-item short-form (SF-36) Health Survey. Median SF-36 dimension scores ranged from 55 to 100 for caregivers and from 46 to 78 for patients. Although the QoL of MS carers was not as severely affected as that of patients, caregiving was associated with lower mental health, vitality and general health scores, compared to healthy subjects. Multivariate analyses revealed significant differences between the predictors of patient QoL and caregiver QoL. The main predictors of patient QoL were Expanded Disability Status Scale (EDSS) score, MS course, fatigue and depression. Female gender and advanced age were the main predictors of lower QoL in caregivers. In addition, patient BDI score was found to be a significant predictor of almost all caregiver SF-36 dimension scores, while EDSS score, disease duration and course, and patient therapeutic characteristics were found to be predictors of some caregiver SF-36 dimension scores.

Rivera-Navarro et al. (2009) studied 278 caregivers of persons with MS, recruited from a Spanish cross-sectional survey, measuring health-related quality of life by the 36-Item Short-Form Health Survey (SF-36) and burden by the Zarit Caregiver Burden Interview. Of the caregivers, 56.8% were female and their mean age was  $50.1 \pm 12.6$  years. Their main relationship with the person with MS was spouse/partner (52.9%) and son or daughter (25.9%). Caregiver General Health, Mental Health, Bodily Pain, and Role-emotional Functioning were the most affected dimensions on the SF-36. Multiple regression analysis showed that independent and significant predictors of burden were Role-emotional Functioning and Vitality dimensions SF-36 scores of caregivers, and the Expanded Disability Status Scale scores. The total adjusted variance explained by these variables (adjusted R<sup>2</sup>) was 0.512. Emotional factors and the disability of the person with MS were major predictors of burden.

In Waldron-Pennine et al. study (2009) the participants were 64 caregivers of patients with MS and the patients for whom they care. Multiple

regression analysis indicated that caregiver perception of illness uncertainty and patients' unawareness of deficits have unique value in predicting caregiver life satisfaction, even after accounting for general financial status. Gender and level of social support were also important contributing factors to caregiver life satisfaction. The findings suggest that duration and severity of the patients' illness take a greater toll on life satisfaction of caregivers with low versus high social support, particularly among women caregivers.

The most commonly used generic questionnaires assessing quality of life of carers in the MS are: Burden Interview (BI index), Caregiver Burden Scale (CBS), Caregiver Reaction Assessment (CRA), Caregiver Strain Index (CS), Life Situation Questionnaire (LSQ) and the Sense of Competence Questionnaire (SCQ). Besides them the 26-item WHOQOL-Bref, SF-36 Health Survey and the Zarit Caregiver Burden Interview (ZCBI) are also used. The latter (1980) consists of 22 items assessing the impact of disability on the patient's physical health and emotional state, social and financial repercussions. Range of scoring is from "never" (0 points) to "almost always" (score 4), the final sum is from 0 to 88. The higher the score, the higher the perceived burden of carer - CB (caregivers burden).

In 2011, Benito-León et al published the first specific questionnaire for assessing the quality of life of carers of patients with multiple sclerosis: caregiver health-related quality of life (HRQOL) in Multiple Sclerosis. Subjective factors in QoL in MS patients include perception of symptoms, level of fitness, self-image, satisfaction with family life, work, the economic situation, the interaction with other people, social support and life in general. To the objective factors include the clinical picture of disease, social status, social and living conditions and the number and intensity of social contacts. CAREgiver health-related Quality Of Life in MS - CAREQOL-MS consists of 24 items comprising the four sub-scales: physical stress / global health, social integration, emotion and the need for assistance / emotional reactions. Questionnaire items were derived from a literature review and the views of patients, caregivers, and experts. They are scored on a 5-point Likert-type scale (higher scores reflecting worse HRQOL). High correlation was found between the sub-scales CAREQOL-MS and Zarit scale (ZCBI) and moderate correlation with SF-36. Correlation was observed between the increase of CAREQOL-MS (worse quality of life associated with the disease - HRQOL) in carers, age and EDSS scores (Expanded Disability Status Scale). The average standard error for the sub-scales ranged from 2.01 to 2.43. These results gave evidence for the usefulness and satisfactory psychometric properties of the questionnaire CAREQOL-MS.

Khan et al. (2007) made in a cross-sectional survey of 62 informal caregivers and 101 participants with confirmed MS and quantified physical and cognitive disability. The mean caregiver age was 54

years (range 37 - 62). The mean caregiver strain score was 5.63 (SD 3.63). Twenty-six of 62 (42%) caregivers reported strain for items such as emotional adjustments, demands on time, change in personal plan and disrupted sleep. Caregiver burden was higher in those caring for the more severely affected persons with MS, especially those with higher depression, anxiety and stress levels. The caregiver strain correlated with a lower QoL in both the person with MS and their caregiver, but not with their self-efficacy scores.

Leibach et al. presented in recent report (2016) results of study which examined the association between mental health (Patient Health Questionnaire-9, Satisfaction with Life Scale, Rosenberg Self-esteem Scale, State-Trait Anxiety Inventory) and HRQOL (36-item Short Form Health Status Survey) in 81 Mexican MS caregivers. A canonical correlation analysis uncovered a large, significant overall association between mental health and HRQOL. The authors concluded that these findings demonstrated a strong association between HRQOL and mental health, which points to directions for future studies on interventions for MS caregivers, particularly in Mexican and other Latino populations.

Buhse et al. (2015) conducted study to determine which factors (clinical and demographic) are associated with mental and physical health-related quality of life (HRQOL) for caregivers of older persons with MS. The Andersen's Healthcare Utilization Model guided this study. They concluded that the challenges older caregivers face when caring for older persons with MS have been shown to affect their mental and physical QOL. Nurses who care for older patients with MS will increasingly rely on older caregivers to provide patient-centered interventions.

## BURDEN OF MS CAREGIVERS

There are many different definitions of the burden of taking care of the chronically sick persons in the literature: burden, strain, stress, distress. Pearlin and colleagues (1990) refer to them as physical, mental, emotional, social and financial problems, associated with families that care for patients. This assistance is usually provided by a close family member, often a spouse or child, usually a daughter who lives with the patient. Carers provide basic personal hygiene, assistance with daily activities, provide emotional support, arrange for medical services and social assistance.

Caring for a patient may have an impact on the objective and subjective aspects of a guardian, such as physical and emotional health, morale, job, finances, social activity, relationships and sex life. In studies assessing the psychological consequences of care a higher level of anxiety and depression in caregivers than in the general population has been reported.

Carers provide informal care ranging from physical help to psychosocial support. As a result,

these carers may experience high levels of burden, associated with characteristics of the patients and of the carers themselves. This burden can result in a deterioration of the carers' health status, social life and well-being.

Caring for MS patients is burdensome and may impact several objective and subjective aspects of caregiver's life, such as physical and emotional health, morale, work life, finances, social mobility, interpersonal relationships and sex life. In the studies on psychological consequences of caregivers of post stroke patients it have been reported that an elevated level of anxiety and depression was present in 17% to over 50% of subjects and in most these studies it was higher than both available norms or comparison of control groups (Opara & Jaracz 2013).

The severity of burden perceived by carers depends on a variety of factors, both from caregivers' and patients' side. They may be summarized as follow: (1) factors from a patient's side: low functional status, the presence of depression, the presence of behavioral and cognitive disturbances, being a male, older age; (2) factors from a caregiver's side: older age, being a female, not being employed, being the care recipient's daughter-in-law, amount of surveillance time, the presence of depression, the presence of disability, sense of coherence, and non-informal social support of the caregiver (Hillman 2013).

Pearlin et al. (1990) divided stressors into two parts: primary stressors are hardships and problems anchored directly in caregiving. Secondary stressors fall into two categories: the strains experienced in roles and activities outside of caregiving, and intra-psychoic strains, involving the diminishment of self-concepts.

The burden and strain have been the dominant paradigm in assessing the impact of the disease on caregivers life. These studies however capture only the negative consequences of the caregiving role. It is worth to highlight that caregivers not only perceive burden, but also may experience positive emotions such as: satisfaction, pride, gratification and feeling closer to their partners (Opara & Jaracz 2013).

Buhse (2008) wrote that partners of people with MS often become caregivers, adding to the demands and challenges of family life. As the individual's disease progresses, the capacity for self-care may decrease, and the individual may require daily assistance from family members. However, the daily assistance that family members provide to a disabled spouse, parent, partner, or child can take a physical and economic toll on the caregiver, causing caregiver burden. Caregiver burden is a multidimensional response to physical, psychological, emotional, social, and financial stressors associated with the caregiving experience. Caregivers who experience burden are more likely to have a higher risk of depression and a lower quality of life. Early recognition of caregiver burden is important in determining appropriate interventions.

Hillman indicated in 2013 that thirty percent of persons with multiple sclerosis require caregiving owing to their disability, and 80% of care to MS persons is provided by informal unpaid caregivers. The average caregiver is male, in a spousal/partner relationship with the MS person, and provides more than four hours per day of care for many years. The physical, emotional, and time-intensive nature of caregiving for MS patients frequently impairs the caregiver's own physical and emotional health.

In Akkuş study (2011) 49 caregivers of persons with multiple sclerosis (MS) were assessed using the Zarit Caregiver Burden Interview (ZCBI). Most of the caregivers (63.3%) were females with a mean age of 42 years, and 55% of the caregivers were spouses. The majority of caregivers were involved in bathing (59%) and dressing (55%) activities. A significant correlation exists between the ZCBI and dimensions of the Psychological and the Social Needs Scale (hopelessness, conflict in decision making, leisure activity deficit and social isolation). The following variables increased the ZCBI scores for caregivers: insufficient income; unemployment; presence of chronic disease; financial problems; difficulties in maintaining responsibilities; caregiver responsibilities involving dressing and positioning of the patient.

In a report published in 2011 Argyriou et al. described 22 male and 13 female primary caregivers (mean age 47 years), and an equal number of patients with MS. Caregivers experienced higher degree of anxiety than depression. Highly educated caregivers were more prone to manifest increased levels of anxiety and depression. They concluded that study group was psychologically burdened to a significant degree, a fact that obviously deteriorates their QoL.

Buchanan et al. (2010) collected data from a national survey of informal caregivers and analyzed characteristics associated with burden among male informal caregivers. In results greater burden among male caregivers was associated with significantly greater hours per week providing assistance ( $P = 0.009$ ) and significantly greater restriction on the caregiver's ability to perform daily activities ( $P < 0.001$ ) due to assisting the person with MS. They found a strong association between the perception of burden and the mental health status of the male caregiver ( $P < 0.001$ ). The authors concluded that those findings highlight the strong association of caregiver burden and the Mental Component Summary of the SF-8. Reducing burden may improve the mental health of informal caregivers. Health professionals treating either male caregivers or people with MS should be sensitive to the impact that providing assistance has on the mental health of informal caregivers.

Chipchase & Lincoln examined in 2001 factors associated with carer strain in carers of people with MS. Problems with everyday memory and activities of daily living were found to be associated with carer strain. Strained carers perceived strain to be a consequence of the memory problems ( $p < 0.01$ ).

Aspects of the memory problems related to carer strain were the amount of time a carer could spend alone ( $p = 0.01$ ), the carer's mood and less sympathetic feelings towards the person with MS ( $p < 0.05$ ). Strained carers had more desire for other people to help the person with MS deal with the memory problems by themselves than carers who were not under strain ( $p = 0.03$ ). Authors' conclusion: carer strain was associated with memory problems experienced by people with MS.

Finlayson and Cho presented in 2008 a descriptive profile of caregivers of older adults with MS and the assistance they provide. The purpose of their telephone interview was to describe and compare spousal and non-spousal 302 caregivers of older adults with multiple sclerosis (MS), the nature and extent of assistance they provide, and the challenges they experience in the course of their caregiving role. In results spousal and non-spousal caregivers differed in age, sex, location of residence, and employment status. Spousal caregivers assisted with more activities, although non-spousal caregivers provided equivalent caregiving time. Twenty percent of caregivers spent more than 3.5 h per day caregiving. Caregiving time was influenced by cognitive and ADL status of the person with MS, and the number of caregiving activities performed. Challenges reported by caregivers were similar. The authors concluded that both spousal and non-spousal caregivers of older adults with MS provide substantial assistance, and experience many challenges. Rehabilitation professionals need to be aware of the diversity of caregivers and the assistance they provide to facilitate appropriate support and resources.

Social Provisions Scale created in 1984 by Daniel Russell and Carolyn Cutrona consists of 24 items belonging to six sub-scales: attachment, social integration, opportunity for nurturance, reassurance of worth, reliable alliance and guidance.

Peters et al. made in 2013 a cross-sectional survey of carer quality of life and experiences of health services across three neurological conditions. A cross-sectional survey was conducted of 1910 (37.4%) of carers of 5109 people with motor neuron disease (MND) ( $n=434$ , 54.9%), multiple sclerosis (MS) ( $n=721$ , 30.7%) and Parkinson's disease (PD) ( $n=755$ , 38.2%). Carers completed a generic health status measure (SF-12), a carer strain measure (Carer Strain Index- CSI) and a newly developed questionnaire on health and social care experiences. In results: carer well-being was found to be compromised and differed significantly between the three conditions. Furthermore, a considerable number of carers experienced problems with aspects of health and social care, although there was no clear pattern according to the condition that was cared for. The total number of problems reported did not differ significantly between conditions but was significantly (all  $p < 0.001$ ) associated with carer quality of life (both physical and mental health) and strain, even when other influencing

factors (demographic and caregiving variables) were corrected for. The association was particularly strong for carer strain, and less strong (but still significant) for quality of life. Authors' conclusion: those results show that carer well-being is compromised, in line with previous studies. Furthermore, the link of carer well-being to the number of problems reported suggests that minimizing problems experienced could improve carer well-being. This stresses the importance of health and social services appropriately supporting carers.

Due to GEDMA study Rivera-Navarro et al. (2008) stated that people with MS reported the social stigma attached to suffering from the disease. Many of the caregivers thought that patients with MS did not accept the disease and felt that over-protection was of little help in coming to terms with the disease and should therefore be avoided. Remunerated work was described by caregivers as a factor that, at the same time, generated and protected the burden. In conclusion: the social stigma, the lack of work and coming to terms with MS were the greatest issues for the patient, while support from the family network, the relationship that should be established with the patient, the impact of MS on children and the role played by remunerated work were the main dimensions of the disease for the caregiver.

Last four reports comes from last two years. In a recent study Penwell-Waines et al. (2016) applied the Stress/Health Model to examine a novel approach for promoting stress management among 67 caregivers of persons with MS, who often face unique caregiving challenges. Hierarchical regressions indicated that caregiver distress (i.e., emotional burden) and engagement in other health-promoting activities (i.e., controlling alcohol use) were the best predictors of caregiver stress management. Communication with the MS care recipient's health provider about caregiver engagement in health-promoting activities was associated with caregiver stress management, but not significantly more so than explained by the other factors (i.e., caregiver distress and engagement in health-promoting behaviors). Authors' conclusion: more controlled study would be indicated to further explain how to encourage, within the medical setting, caregiver engagement in self-care activities.

French researchers confirmed in 2015 that home care for patients with MS relies largely on informal caregivers. Bayen et al. (2015) assessed informal caregivers objective burden measuring informal care time and using Zarit Burden Inventory (ZBI). Informal caregivers (N = 99) were spouses (70%), mean age 52 years, assisting disabled patients with a mean EDSS (Expanded Disability Status Scale) of 5.5, with executive dysfunction (mean Dysexecutive questionnaire of 25) and a duration of MS ranging from 1 to 44 years. Objective burden was high (mean 6.5 hours/day), mostly consisting of supervision time. Subjective burden was moderate (mean ZBI = 27.3). Multivariate analyses showed that both burdens were positively correlated with higher levels of EDSS and

Dysexecutive questionnaire, whereas coresidency and informal carers female gender correlated with objective burden only and informal carers poor mental health status with subjective burden only. When considering MS aggressiveness, it appeared that both burdens were not correlated with a higher duration of MS but rather increased for patients with severe and early dysexecutive function and for patients classified as fast progressors according to the Multiple Sclerosis Severity Score. Authors conclusion: evaluation of MS disability course and informal carers personal situation is crucial to understand the burden process and to implement adequate interventions in MS.

Lee et al. (2015) explored gender differences in the need for various supports and type of social support needed, caregiver strain, and quality of life among caregivers for individuals with MS. Analyses revealed gender difference among important psychosocial variables. Specifically, women reported higher levels of caregiver strain, higher needs for emotional support, and higher perceived social support. Additionally, multiple regression analyses revealed an inverse relationship between expressed emotional needs and QoL for men, but not for women. Authors conclusions: MS caregivers experience significant strain that diminishes QoL. Social support and needs fulfillment can act to buffer this stress; however, results indicate that this varies by gender, with gender differences observed in strain, perceived support, and expressed needs among MS caregivers.

In recent report (2016) Giordano et al. described results of multicenter study on wellbeing and burden in 78 carers of people with severe multiple sclerosis (PwSMS) in the frame of PeNSAMI project. They used cross-sectional assessment of health-related quality of life (HRQOL) with SF-36, Hospital Anxiety and Depression Scale (HADS) and 22-item Zarit Burden Interview (ZBI). Carers (61% women, mean age 60.2 years, 53% spouse/partner) had significantly lower HRQOL (all SF-36 scales) than the norm, especially for Role Limitation Emotional/Physical, and Emotional Wellbeing. Sixty-eight percent had pathologic ( $\geq 8$ ) Anxiety, and 44% had pathologic Depression scores on HADS. Nonetheless, perceived carer burden was only moderate (mean ZBI score 35.6, SD 14.3). High carer anxiety ( $p < 0.0001$ ), low household income ( $p = 0.009$ ), and living with the PwSMS ( $p = 0.02$ ) were independent predictors of perceived burden. Authors' conclusions: caring for PwSMS has a detrimental effect on HRQOL and psychological wellbeing. High carer anxiety, low economic status, and living in predict higher burden. It is crucial to recognize PwSMS carers as full partners in the provision of care, and to respond to their own needs.

## SUMMARY

Multiple sclerosis (MS) is one of most disabling disorders of the central nervous system. Caregivers of individuals with MS may experience unique caregiver

strain due to the age at onset and progressive nature of the disease. Additionally, because MS is more prevalent in women, men often become spousal caregivers. This places women in the position of being care recipients rather than caregivers. Some results also supported hypothesis that female caregivers reported a higher need for emotional support than male caregivers. As with female caregivers, decreased emotional support predicted poorer QoL among male caregivers.

Caring for a MS patient, as have been shown in the literature, may negatively impact several objective and subjective aspects of caregiver's life, such as physical and emotional health, morale, work life, finances, social mobility, interpersonal relationships and sexual life. In studies assessing the psychological consequences of care a higher level of anxiety and depression in caregivers than in the general population has been reported. Caregivers who experience burden are more likely to have a higher risk of depression and a lower quality of life. Early recognition of caregiver burden is important in determining appropriate interventions.

The severity of burden perceived by carers depends on a variety of factors, both from caregivers' and patients' side. They may be summarized as follow:

- (1) factors from a patient's side: low functional status, the presence of depression, the presence of behavioral and cognitive disturbances, being a male, older age;
- (2) factors from a caregiver's side: older age, being a female, not being employed, being the care receiver's daughter-in-law, amount of surveillance time, the presence of depression, the presence of disability, sense of coherence, and non-informal social support of the caregiver.

The above review demonstrates that the QoL reduction and burden among persons caring for MS patients is significant and that the burden is influenced by several factors some of which are modifiable. It means that there is a room for professional interventions to reduce caregivers' strain and in the result to improve their QoL.

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