



## Low quality of life and psychological wellbeing contrast with moderate perceived burden in carers of people with severe multiple sclerosis



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### ABSTRACT

**Background:** Few studies have investigated wellbeing and burden in carers of people with severe multiple sclerosis (PwSMS).

**Objectives:** To assess the impact of providing care to PwSMS, and explore variables associated with perceived carer burden.

**Methods:** Cross-sectional assessment of health-related quality of life (HRQOL), mood symptoms (Hospital Anxiety and Depression Scale, HADS), and perceived carer burden (22-item Zarit Burden Interview, ZBI) in 78 PwSMS carers. Multivariate linear regression explored carer and PwSMS factors associated with ZBI score.

**Results:** 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.

**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.

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### 1. Introduction

Around 15% of people with multiple sclerosis (MS) have a progressive course from the outset (primary progressive MS), and a further 65% develop progressive disease after a variable period with

relapsing–remitting course (secondary progressive MS) [1]. For those with primarily or secondarily progressive MS, treatment options to delay or prevent further clinical worsening are limited [2] and life expectancy is reduced by about a decade [3]. Post-marketing studies on disease-modifying MS treatments suggest that they may prolong survival [4]. Thus, people with MS can live for many years in a highly dependent condition.

A systematic literature review on 2097 carers of people with MS at all disease stages [5] revealed a huge impact on several aspects of carer life. More recent studies found reduced carer mental health, physical health, and health-related quality of life (HRQOL) [6–16].

We found only two studies that focused on carers of persons with severe MS (PwSMS), both of which used a qualitative approach. Golla et al. recently assessed the unmet needs of 12 carers of PwSMS in Cologne, Germany [17]. They found that carers and PwSMS formed a tight

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dyad, such that carers tended to group the unmet needs of the PwSMS with their own and rarely focused on their own wishes and restrictions. Similarly, a qualitative Italian study [18] uncovered emotional 'contagion' between PwSMS and their carers: the latter felt themselves to be the exclusive interpreters and providers of their loved ones' needs, and reported a profound sense of isolation and fear for the future.

In developing best practices to improve outcomes for people with chronic and progressive neurological diseases, it is important to gain insight into levels of burden, psychological distress, and HRQOL in carers [19]. In the present study, we assessed the consequences of providing care to PwSMS, and explored factors associated with perceived carer burden. The study was a secondary (cross-sectional) analysis of baseline data of the ongoing PeNSAMI trial [20], conducted on Italian PwSMS and their carers. Carer outcome measures were the 22-item Zarit Burden Interview (ZBI) [21,22], the Short Form-36 (SF-36) [23], and the Hospital Anxiety and Depression Scale (HADS) [24].

## 2. Methods

### 2.1. Ethical approval

The study was approved by the Ethics Committees of the C. Besta Neurological Institute and Foundation, Milan; the S. Lucia Foundation, Rome; and the University Hospital of Catania. The trial is registered with Controlled Clinical Trials (trial registration number ISRCTN73082124).

### 2.2. Design and participants

The ongoing PeNSAMI trial to determine the effectiveness of a home-based palliative approach for PwSMS and their carers has been described in detail elsewhere [20]. The present cross-sectional study is a secondary analysis of selected baseline (pre-randomization) data. The carer was a family member, relative, friend, next of kin or key decision maker, as designated by the (cognitively competent) MS patient. Paid carers were included, provided they were the patient's next of kin or a key decision maker. Carers of PwSMS with severe cognitive compromise were designated by the patient's referring physician. Informed written consent was obtained from all patients and carers during pre-study evaluation.

### 2.3. Outcome measures

Three questionnaires (cited in order of administration) were completed by carers: HADS [24], SF-36 [23], and ZBI [21,22]. Carers of PwSMS with severe cognitive compromise also completed carer versions of the Core-Palliative care Outcome Scale (Core-POS) [25,26] and Palliative Care Outcome Scale-Symptoms-MS (POS-S-MS) [27].

HADS consists of 14 multiple choice (0–3 Likert scale) items probing symptoms of anxiety (7 items) and depression (7 items). HADS Anxiety and Depression scores range from 0 (no symptoms) to 21 (most severe symptoms) [24].

SF-36 is a widely-used self-reported generic measure of HRQOL consisting of 36 items in eight domains (Physical Functioning, Social Functioning, Role Limitation Physical, Role Limitation Emotional, Pain, Vitality, Mental Health, and General Health) grouped into two composite scales (Physical Health Composite, PHC and Mental Health Composite, MHC) [23].

ZBI is the most widely-used instrument for measuring carer subjective burden [22,28,29]. It contains 22 questions each with five possible Likert-like responses, ranging from 0 "never" to 4, "nearly always". Total score ranges from 0 to 88, a higher score indicating greater perceived carer burden.

We used the existing Italian versions of HADS [30], SF-36 [31], ZBI [21], and Core-POS; we translated the POS-S-MS into Italian (forward and backward translation procedures) from the original English version

[32]. Household income was obtained from the Italian Revenue Agency - Tax Register Information System.

### 2.4. Statistical analyses

Continuous data were summarised by means and standard deviations, or medians and ranges or interquartile ranges (IQRs), as appropriate. Categorical data were summarised by frequencies. The normality of the distribution of variables was tested using the Shapiro–Wilk W test. Differences across centers were tested by Kruskal–Wallis or ANOVA for continuous variables, and chi-square test for nominal and ordinal variables. Internal consistency was assessed by Cronbach's alpha, with values above 0.70 considered to indicate good internal consistency [33]. We calculated the percentages of subjects with minimum and maximum scores: values >20% indicated a floor or ceiling effect. Item-total correlations in the 0.30–0.70 range were considered adequate [33]. SF-36 scale scores for carers were compared with Italian norms ( $n = 2031$  adults) [31] using two-sample with unequal variances  $t$ -tests.

We used linear regression modeling to investigate variables associated with ZBI score (dependent variable). The following independent variables were investigated: carer variables – gender, age, education, living with the PwSMS, HADS Anxiety and Depression scores, SF-36 PHC and MHC scores; PwSMS variables – gender, age, education, age at MS diagnosis, course, presence of severe cognitive compromise, Expanded Disability Status Scale (EDSS) score [34], Functional Independence Measure (FIM) score [35], Core-POS score, POS-S-MS score, number of relatives living with him/her, and household income.

For HADS Depression, the cutoff was the pathologic score ( $\geq 8$ ); for the other independent continuous variables with non-normal distribution (EDSS, FIM, POS-S-MS, carer age, PwSMS age, age at MS diagnosis, number of relatives living with the PwSMS, and household income) the cutoff was the median. Independent variables significant in the univariate analyses were included in a multivariate model using a stepwise approach. The normality of residuals was checked using kernel density, standardized-normal, and quintile-normal plots; heteroskedasticity was assessed with the Breusch–Pagan test; multicollinearity was assessed by the variance inflation factor (acceptable values < 10). All statistical tests were two-tailed; differences were considered significant at an alpha level of <0.05. Data were analyzed using Stata release 12 (Stata Corp LP, College Station, TX, USA).

## 3. Results

Between January and November 2015, 78 PwSMS-carer dyads received the baseline visit. Table 1 shows information on carers and the PwSMS. Mean carer age was 60.2 years (range 23–84); most (62%) were women. Fifty-three percent were spouses of the PwSMS, 15% parents, 10% sons/daughters, and 17% other relatives; 3 (4%) were paid carers. The latter were immigrant women (two from Romania and one from El Salvador) in Italy from 7, 10 and 12 years; two cared for the PwSMS for 2 years, one for 6 years; two were 31 and one 56 years old; two had secondary education and one college education.

PwSMS (55% women; mean age 59.2 years, range 41–80) were diagnosed at a mean age of 37 years (range 16–66); median EDSS score was 8.5 (IQR 8.0–9.0); median FIM score was 48 (IQR 40–60; Shapiro–Wilk W test,  $p = 0.02$ ); 19% had severe cognitive compromise. Median household income in 2014 was € 32,159 (IQR 17,883–51,495), with positively skewed distribution ( $p < 0.0001$ ).

### 3.1. Health-related quality of life and mood symptoms

All eight SF-36 scale scores were lower ( $p < 0.001$ ) than the Italian norm [31], the most important differences being for Role Limitation Emotional – mean score 48.9 (95% confidence interval, CI 39.8–58.0) vs. 76.2 (95% CI 65.7–67.5) for the Italian norm; and Role Limitation

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