Burden and health-related quality of life among caregivers of MND patients

# Introduction

# Method

## Data and variable

A cross-sectional study of caregivers of XXX was carried out in WHERE in WHEN. Caregivers were included if BRIEF INCLUSION CRITERIA [cite trial]. Data were collected using a questionnaire completed during an in-person interview.

The first set of variables were caregiver sociodemographic characteristics.[[1]](#footnote-1) such as sex (DEFINE), age (DEFINE), level of education (DEFINE), employment status (DEFINE). We also asked respondents if they had any medical conditions.

The second set of variables were psychosocial, including coping strategies, social support, self-esteem, anxiety, and depression.

The third set of variables were caregiving context, including relationship with care recipient (DEFINE), whether living with patient (DEFINE), the type of support provided or care demands (DEFINE), intensity of caregiving activities (DEFINE), and how long has been looking after (DEFINE).

We also collected information on characteristics of care recipient. These were sex of care recipient (DEFINE), age of care recipient (DEFINE), severity of the disease (DEFINE), and disease duration (DEFINE).

The Zarit Burden Interview (ZBI) is the most widely-used instrument for measuring caregiver subjective burden [15], and we used the validated xxx version [16]. The ZBI contains 22 five-point Likert-style questions with reply options ranging from 0 “never” to 4, “nearly always”. The total score ranges from 0 to 88, with a higher score indicating a greater perceived care burden. The cut-off points are: 0 to 20 points = little or no burden; 21 to 40 = mild to moderate burden; 41 to 60 = moderate to severe burden; 61 to 88 = severe burden.

## Statistical analysis

Descriptive statistics including means, standard deviations, frequencies, and percentages were used to analyse the data.

Normality of the primary outcome was tested using the Kolmogorov-Smirnov test, and normal distribution of data was not confirmed. To meet model assumptions of normality, the ZBI total score underwent square root transformation.

Univariate linear regression was used to examine the direction and size of the relationships between caregiver burden and the variables examined, i.e., caregiver characteristics, caregiver resources (internal and external), caregiver-care recipient relationship, intensity of care, and care recipient characteristics.

To test the extent to which the variables explained caregiver burden, we will conduct a hierarchical (block-wise) multiple regression analysis, with XX blocks of variables. The variables that will compose the blocks used in the regression model will be selected by adopting a critical level of significance (p ≤ 0.10|0.05) in the univariate analysis. The first block will include caregiver characteristics as the predictors. We will add caregiving activities, caregiver resources, and care recipient characteristics as predictors in blocks two to four, respectively. Results are presented as coefficients (change in ZBI) and standard errors. The regression models included the following indicators: F-statistic and the corresponding p-value, adjusted R2, change in adjusted R2, and deviance statistics (AIC/BIC).

Regression diagnostics

Multicollinearity: Drop a variable was dropped if the variance inflation factor (VIF) is 10.

All analysis will be conducted using Stata version 18.0 (StataCorp, College Station, Texas, USA).

# Results

## Caregiver characteristics and caregiving context

## Patient characteristics and disease severity

Table 1. Characteristics of patients with motor neuron disease, their caregivers, and caregiving context at baseline from the COMMEND trial.

|  |  |
| --- | --- |
|  | Mean (SD) or n (%) |
| **Caregivers, N=85** |  |
| Age in years | 60.0 (12.2) |
| Female sex | 59 (69.4%) |
| Marital status | 81 (95.3%) |
| In paid employment | 41 (48.2%) |
| Relationship with patient |  |
| Spouse/partner | 70 (82.4%) |
| Child | 9 (10.6%) |
| Other family/friend | 6 (7.1%) |
| Years as primary caregiver | 1.7 (2.6) |
| Hours per week in caregiving | 53.7 (64.3) |
| **Patients, N=85** |  |
| Age in years | 62.5 (10.9) |
| Female sex | 35 (41.2%) |
| Marital status | 76 (89.4%) |
| In paid employment | 25 (29.4%) |
| Patient with comorbidity | 36 (42.4%) |
| Number of comorbidities | 0.6 (0.7) |
| Years since diagnosis | 1.6 (2.9) |
| King's stage at baseline |  |
| 1 | 18 (21.2%) |
| 2 | 27 (31.8%) |
| 3 | 35 (41.2%) |
| 4 | 5 (5.9%) |

Data are based on participants with non-missing baseline caregiver burden and quality of life data.

n, number; SD, standard deviation.



Figure 1. EQ-5D-5L utility scores, domain scores and scores by King’s stage

Table 2. Pooled carer ZBI, EQ-VAS, and EQ-5D utility and domain scores by King’s stage1

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Stage 1 | Stage 2 | Stage 3 | Stage 4 | p-value2 |
| ZBI3 | 18.11 | 25.68 | 22.96 | 27.95 |  |
| EQ-VAS4 | 80.94 | 80.39 | 80.66 | 79.79 |  |
| EQ-5D5 | 0.89 | 0.85 | 0.80 | 0.77 |  |
| *EQ-5D domains6* |  |  |  |  |  |
| Mobility | 1.17 | 1.19 | 1.35 | 1.36 |  |
| Self-care | 1.03 | 1.00 | 1.07 | 1.09 |  |
| Usual activity | 1.14 | 1.28 | 1.40 | 1.55 |  |
| Pain/Discomfort | 1.34 | 1.44 | 1.65 | 1.97 |  |
| Anxiety/Depression | 1.31 | 1.61 | 1.83 | 1.73 |  |

1 Data from all caregivers at all timepoints (baseline, 6 months, and 9 months) have been pooled.

2 Comparisons of outcomes between King’s stages using analysis of variance (ANOVA)

3 ZBI total score range = 0–88, higher scores indicate greater burden

4 EQ-VAS score range = 0–100, higher scores indicate better health-related quality of life.

5 EQ-5D score range = 0 to 1.0, higher scores indicate better health-related quality of life.

6 EQ-5D domain scores range = 0-3, higher scores indicate greater restriction by domain

Table 3. Means (standard deviation) of caregiver ZBI, EQ-VAS, and EQ-5D scores and results of t-tests comparing changes over time.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Component | Baseline, N=85 | 6 months, N=68 | 9 months, N=66 | Baseline vs  6 months1 | 6 months vs  9 months1 | Baseline vs  9 months1 |
| ZBI score | 21.1 (12.2) | 25.8 (14.4) | 25.9 (15.8) | -6.18  p<0.001 | -1.01  p=0.363 | -6.39  p<0.001 |
| EQ-VAS score | 80.0 (18.0) | 81.6 (10.5) | 80.1 (16.5) | -1.77  p=0.355 | 0.56  p=0.769 | -0.84  p=0.743 |
| EQ-5D score | 0.81 (0.19) | 0.84 (0.14) | 0.81 (0.14) | <-0.01  p=0.703 | 0.02  p=0.068 | 0.02  p=0.17 |

EQ-5D, EuroQol 5-dimension questionnaire; VAS, visual analog scale; ZBI, Zarit Burden Interview

1 t-tests using complete data (N=68 for baseline vs 6 months, 62 for 6 months vs 9 months (61 for ZBI), and 66 for baseline vs 9 months (65 for ZBI))

Table 4. Correlations between caregiver ZBI versus EQ-VAS and EQ-5D scores at baseline and 9 months.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | ZBI vs EQ-VAS | | | ZBI vs EQ-5D index | | |
| Time point | n | Coefficient1 | p-value | n | Coefficient1 | p-value |
| Baseline score | 85 | -0.21 | 0.054 | 85 | -0.20 | 0.069 |
| 9 months score | 65 | -0.27 | 0.028 | 65 | -0.38 | 0.002 |
| Change in score2 | 65 | -0.08 | 0.519 | 65 | -0.30 | 0.017 |

EQ-5D, EuroQol 5-dimension questionnaire; VAS, visual analog scale; ZBI, Zarit Burden Interview

1 Spearman correlation coefficients

2 Change in score from baseline to 9 months

1. Ponzio, M., Tacchino, A., Verri, A. et al. Profile and burden of the family caregiver: the caring experience in multiple sclerosis. An observational study. BMC Psychol 12, 173 (2024). https://doi.org/10.1186/s40359-024-01678-w [↑](#footnote-ref-1)