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**OBJECTIVE** Few studies have investigated the wellbeing and burden of carers of people with severe multiple sclerosis (PwSMS).

We assessed 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, SF-36 [1]), mood symptoms (Hospital Anxiety and Depression Scale, HADS [2]), and perceived caregiver burden (22-item Zarit Burden Interview, ZBI [3]) in 78 PwSMS carers participating to the PeNSAMI trial (baseline visit) [4]. Assessment of carer and PwSMS factors associated with ZBI total score.

**RESULTS** Between January-November 2015, 78 PwSMS-carer dyads were assessed (Table 1). Carers (61% women, mean age 60.2 years, 53% spouse/partner) had SF-36 scale scores significantly lower than the Italian norm, the difference being highest for Role Limitation Emotional/Physical, and Emotional Wellbeing (Figure 1). 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, ZBI profile on Figure 2). 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 (Table 2)

Table 1. Characteristics of the 78 carer-PwSMS dyads

Characteristic	Carers	PwSMS
		No (%)
Women	48 (62)	43 (55)
Age (years) <sup>1</sup>	60.2, 61.0 (23–84)	59.2, 58.3 (41–80)
Education: No education completed	0	1 (1)
Primary (5–8 y)	27 (34)	30 (38)
Secondary (12–13 y)	32 (41)	31 (40)
College/University (14+ y)	19 (25)	16 (21)
Occupation: Employed	35 (44)	4 (5)
Retired (age)	25 (32)	10 (13)
Housewife	14 (18)	0
Unemployed	2 (3)	1 (1)
Student	2 (3)	0
Retired (disability)	0	63 (81)
Age at MS diagnosis (years) <sup>1</sup>	–	37.0; 35.5 (16–66)
EDSS score <sup>1</sup>	–	8.5; 8.5 (8.0–9.5)
Severe cognitive compromise	–	15 (19)
Paid caregiver available 24 hours <sup>2</sup>	–	8 (23)
2014 Household income (€) <sup>1,3</sup>	–	39,078; 32,159 (5,862–154,732)
Relation to PwSMS: Spouse/partner	41 (53)	–
Parent	12 (15)	–
Other relative	13 (17)	–
Son/daughter	8 (10)	–
Paid caregiver	3 (4)	–
Friend	1 (1)	–
Living with the PwSMS	69 (88)	–

EDSS: Expanded Disability Status Scale; PwSMS: person with severe multiple sclerosis.  
<sup>1</sup> Mean; median (range).  
<sup>2</sup> Including three who formed part of dyad.  
<sup>3</sup> For two PwSMS, 2013 household income was available

Figure 1. Mean SF-36 scale scores of the 78 carers of PwSMS (red bars) in comparison to the Italian norm (n=2031; blue bars) [2]. All differences (two-sample t-test with unequal variances) are significant ( $p < 0.001$ )

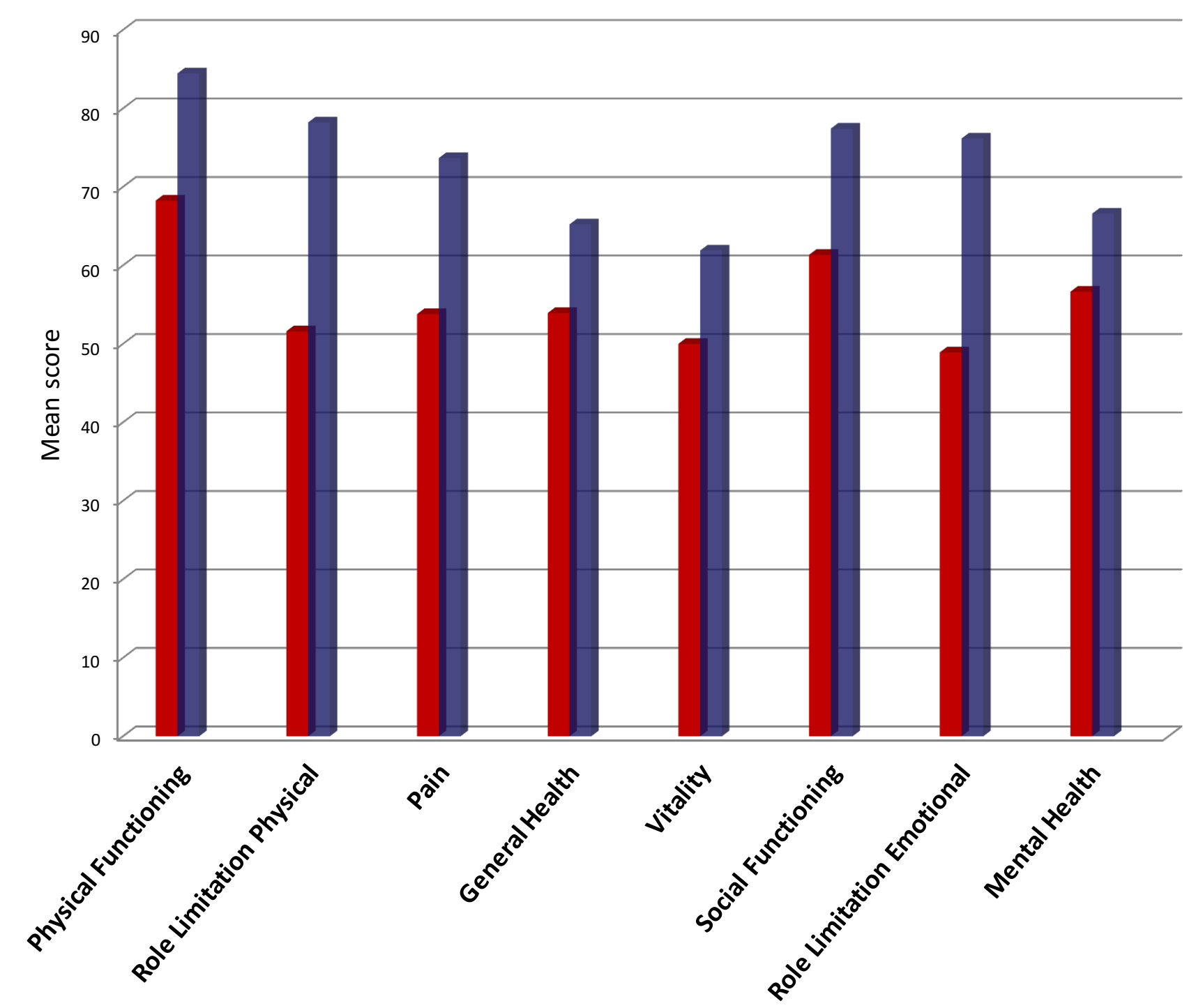


Figure 2. Percentage distribution of responses to the ZBI items. Figures at top of each column are item median value

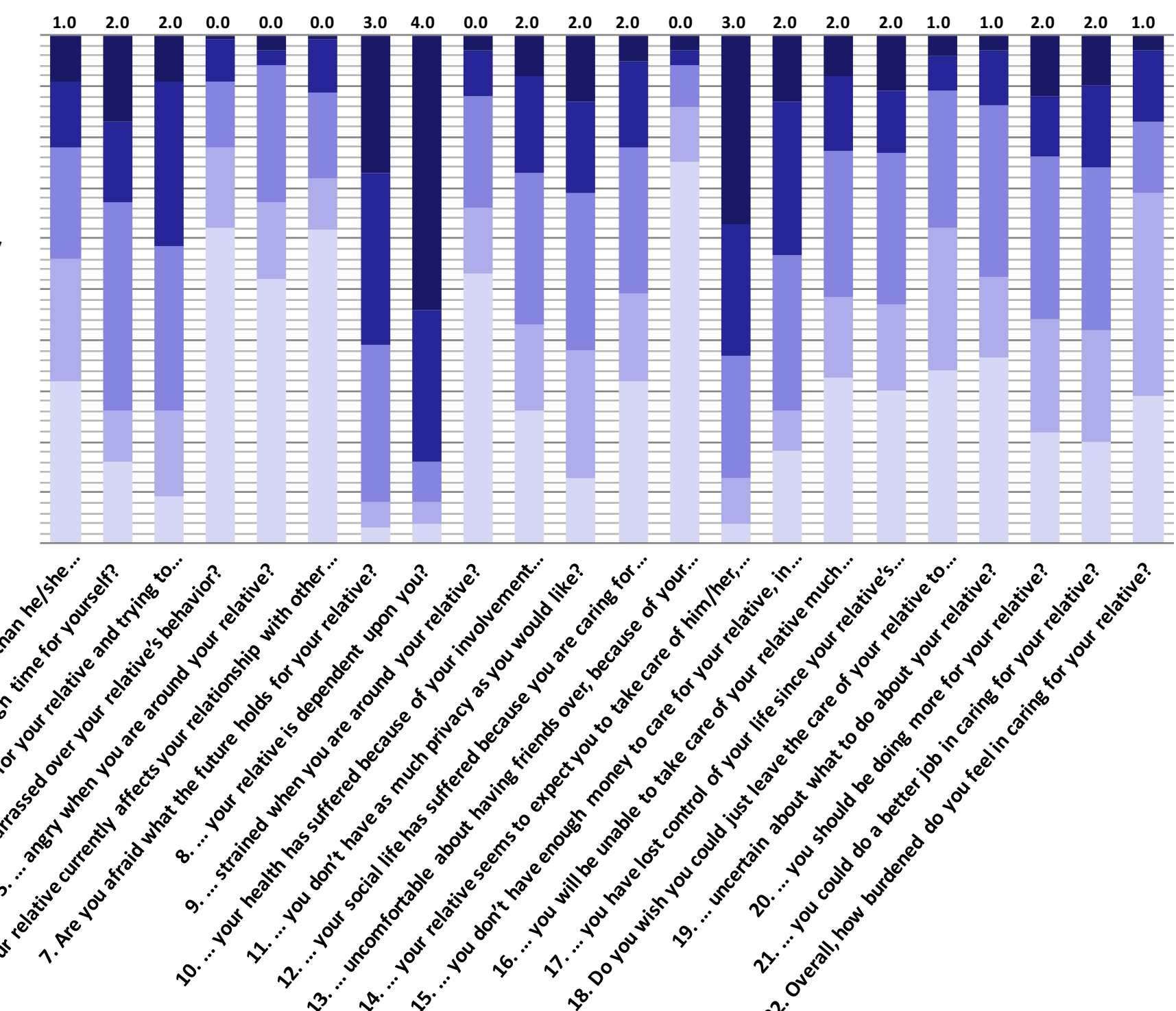


Table 2. Characteristics associated with ZBI total score in linear regression analyses

Characteristic	Univariate		Multivariate*	
	$\beta$ coefficient (95% CI)	P value	$\beta$ coefficient (95% CI)	P value
<b>Carers</b>				
Age > 60 years	0.60 (-5.99 – 7.20)	0.85		
Female sex	3.84 (-2.89 – 10.58)	0.26		
College/university education	-2.58 (-10.17 – 5.02)	0.50		
HADS-Anxiety score $\geq 8.0$	1.92 (1.24 – 2.59)	<0.001	1.84 (1.01 – 2.67)	<0.0001
HADS-Depression score $\geq 8.0$	11.12 (4.98 – 17.26)	0.001	3.10 (-3.27 – 9.47)	0.33
SF-36 PHC score	-0.50 (-0.81 – -0.20)	0.002	0.13 (-0.18 – 0.44)	0.41
SF-36 MHC score	-0.81 (-1.11 – -0.52)	<0.001		
Living with the PwSMS	11.76 (1.90 – 21.62)	0.02	10.47 (1.85 – 19.99)	0.02
<b>Persons with severe MS</b>				
Age > 58 years	6.06 (-0.39 – 12.51)	0.06		
Female sex	-6.86 (-13.30 – -0.42)	0.04	-4.85 (-10.86 – -1.16)	0.11
College/university education	-4.26 (-12.49 – 3.97)	0.31		
Age at MS diagnosis > 35 years	9.97 (3.79 – 16.15)	0.002	4.98 (-0.53 – 10.50)	0.08
Secondary progressive MS	-2.08 (-9.56 – 5.40)	0.58		
Severe cognitive compromise	-0.36 (-8.64 – 7.93)	0.93		
EDSS > 8.5	-10.23 (-17.47 – -2.99)	0.006	-4.85 (-11.52 – 1.82)	0.15
FIM total score > 48	1.02 (-5.59 – 7.64)	0.76		
Core-POS score	0.48 (0.02 – 0.93)	0.04	-0.13 (-0.57 – 0.31)	0.40
POS-S-MS score > 22.5	0.15 (0.25 – 0.54)	0.46		
Household income > € 32,000	-6.79 (-13.20 – -0.37)	0.04	-8.55 (-14.92 – -2.18)	0.009
Centre (Milan, reference): Rome			0.42 (-7.25 – 8.09)	0.80
Composite: PHC: Physical Health Composite; Catania			3.00 (-4.10 – 4.08)	0.40

\* Adjusted  $R^2 = 0.50$ ; Breusch-Pagan test for heteroskedasticity,  $\chi^2 = 2.83$ ,  $p = 0.09$ ; variance inflation factor test for multicollinearity range: 1.2–1.9.

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**CONCLUSIONS**

- Caring for PwSMS has a detrimental effect on HRQOL and psychological wellbeing
- High carer anxiety, low economic status, and living in predict higher caregiver 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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