

Family care in a neurological chronic condition as multiple sclerosis

Michela Ponzio¹, Andrea Tacchino¹, Paola Zaratini¹, Giampaolo Brichetto¹, Mario Alberto Battaglia²

¹Research Area, Italian Multiple Sclerosis Foundation, Genoa, Italy; ²Department of Life Science, University of Siena, Siena, Italy

Introduction To date, in most countries, about 80% of people with multiple sclerosis (PwMS) that need care are covered by unpaid caregivers, usually family members (1). The concept of family care intrinsically involves two individuals in a close relationship. However, most family care research has focused on only one person of the dyad.

Aim To explore how multiple sclerosis (MS) impacts on PwMS and their caregivers, through questions explicitly referred to the role played by MS on domains related to quality and satisfaction of life.

Data and sample enrollment Data come from a cross-sectional study where PwMS, together with their caregivers, were enrolled across MS Clinical Centres, rehabilitation units or among members with MS of Italian MS Society.

Instruments Two comparable parallel questionnaires, following the Engel's biopsychosocial model, were developed specifically for PwMS and their caregivers, respectively. The questionnaire investigated four domains representing the main aspects related to quality and satisfaction of life (mood, future perspectives, social relationships and sexuality). The main domains were identified evaluating the literature related to PwMS quality of life (considering both subjective and objective factors), caregiver burden and study about dyad relationship. Each item used a five-point Likert scale. A standardized total score (STS) was calculated for each domain. A STS of 2.5 or greater was considered burdensome for individuals of the dyad.

Analysis Cronbach α coefficients were calculated to evaluate internal consistency reliability, resulting greater than 0.70 for all domains. Two-tailed paired t-test was used to compare mean STS between PwMS and caregiver responses. Scores correlations were tested using Pearson tests.

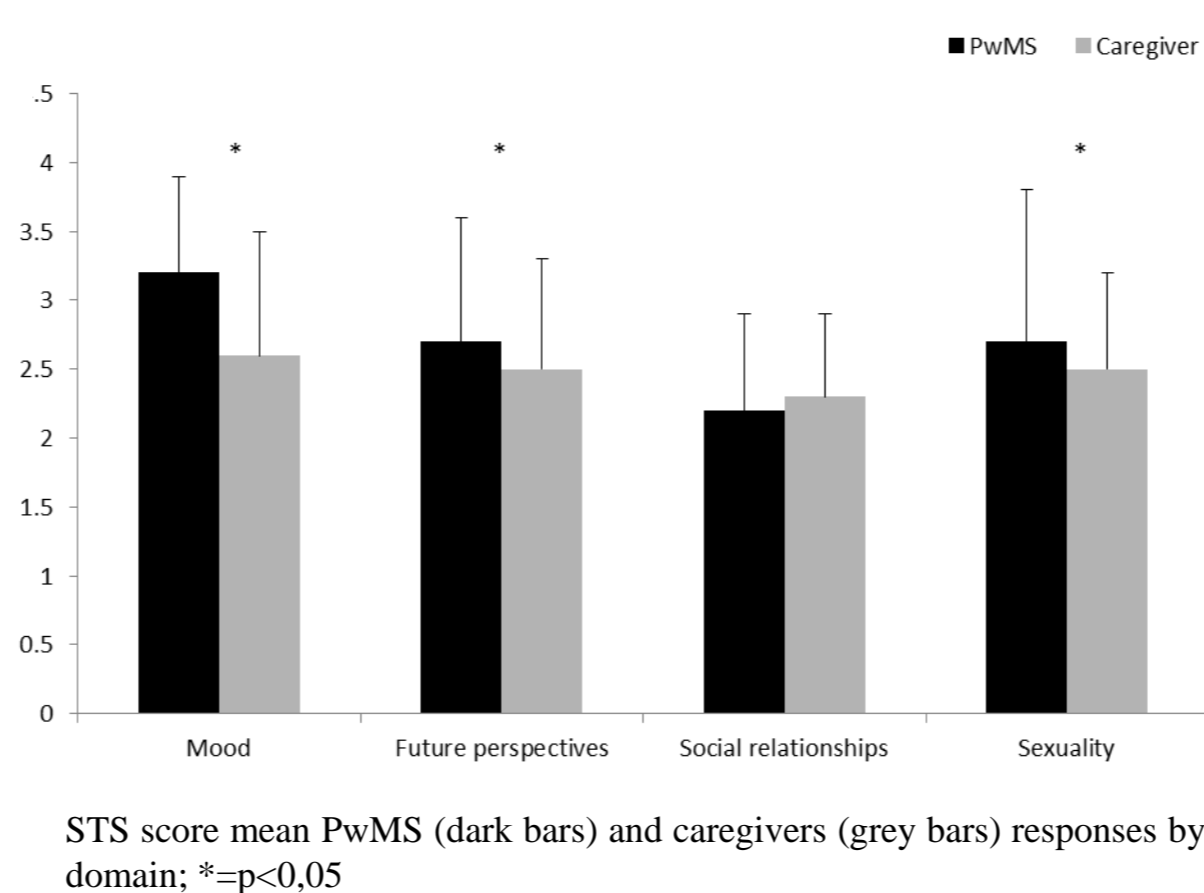
Results A total of 167 dyads were analyzed.

Comparison of questionnaire life domains between PwMS and caregiver

Table 1 Clinical and demographic features of the 167 dyads

Variables	PwMS	Caregiver
Gender, %	M	47.7
	F	52.3
Age, years	mean (SD)	54.8 (13.9)
	range	22-85
Civil status, %	Single	12.2
	Married/living together	78.7
	Separated/divorced	5.5
	Widower	3.7
Employment, %	Currently employed	49.4
	Unemployed	5.4
	Pensioner	28.9
	Student	3.0
	Never worked/housewife	13.3
Education, %	Primary school	43.0
	High school	42.0
	University degree	15.0
Clinical disease course, %	RR	26.1
	SP	45.4
	PP	28.5
Disability level (expressed in EDSS), %	Mild (0-3)	32.1
	Moderate (4-6.5)	49.7
	Severe (>=7)	18.2
Duration of disease, years, mean (SD)		17.6 (10.4)
Relation between patient and caregiver, %	Spouse/consort	69.9
	Friends	2.6
	Son/daughter	5.8
	Parent	15.6
	Other relatives	6.4
*Type care, %	Direct care	74.7
	Surveillance and company	67.4

* categories not mutually exclusive, SD, standard deviation



STS score mean PwMS (dark bars) and caregivers (grey bars) responses by domain; *p<0,05

- For almost all domains PwMS reported a significantly different mean score (higher STSs) with respect to the caregivers.
- Only social relationships domain did not show differences between populations (P=0.0669); a value lower than 2.5 was found for both populations, proving that social life aspects were not a relevant problem for PwMS and caregivers.

Domains	Pearson's correlation
Mood	r = 0.39, P<0.0001
Future perspectives	r = 0.29, P=0.0002
Social relationships	r = 0.41, P<0.0001
Sexuality	r = 0.53, P<0.0001

- The correlation pattern of the PwMS and caregiver responses, showed moderate positive and statistically significant correlation in almost all domains of the questionnaire, only for future perspectives the correlation resulted more weak.

Conclusion In mood, future perspectives, and sexuality domains, the PwMS generally felt as more limited (worse mood, more obstacles in future perspectives and worse quality of the own sexual life) reporting higher STS than their caregivers. The mood domain, for both, was the main problem, pointing out that the preservation of good mood and happiness are crucial for dyad members, suggesting that it should become a priority for healthcare system that should provide strategies to prevent negative impact of chronic disease consequences and to cope with stress.

Overall, the agreement degree of the PwMS/caregiver pairs resulted moderate, only for future perspectives the answers dyad were less in agreement highlighting different expectations. Family care, as a dyadic process, is based on the premise that each participant affects and is affected by the other. Living with a chronic illness is truly a family affair. To improve the illness management, it is essential, therefore, to include family caregivers as members of our health care team and to ensure that they receive the same mental and physical health care and access to wellness that we are responsible to provide to PwMS.

References 1) Carton H, Loos R, Pacolet J, Versieck K, Vlietinck R. (2000). A quantitative study of unpaid caregiving in multiple sclerosis. *Multiple Sclerosis*; 6: 274-79.