

Emotional burden and coping strategies in Amyotrophic Lateral Sclerosis caregivers: the role of metacognitions



Russo M¹, La Foresta S¹, Faraone C¹, Pistorino G², Lizio A³, Vita GL¹, Sframeli M^{1,4}, Di Stefano MG⁴, La Rosa M⁴, Barcellona C⁴, Vita G^{1,4}, Quattropiani C², Lunetta C^{1,3}, Messina S^{1,4}

1 Department of Cognitive Sciences, Psychology, Education and Cultural Studies, University of Messina, Messina, Italy
 2 Nemo Sud Clinical Center for Neuromuscular Disorders, Aurora Onlus Foundation, University Hospital "G. Martino", Messina, Italy
 3 NeuroMuscular Omnicenter, Serena Onlus Foundation, Milan, Italy
 4 Department of Clinical and Experimental Medicine, University of Messina, Messina, Italy

INTRODUCTION

The high caregiver burden in Amyotrophic Lateral Sclerosis (ALS) relates to personal and social restrictions and to psychological and emotional disorders and has been shown to influence patients' psychological status. Metacognition is defined as "the aspect of information processing that monitors, interprets, evaluates and regulates the contents and processes of its organization". Research highlights that dysfunctional metacognitive beliefs are the basis for the development and maintenance of emotional disorders. Evidence from several studies in both clinical and non-clinical samples highlighted the role of dimensions of metacognition as vulnerability factors in predicting development of anxiety and depression symptoms especially in presence of life-stress events. Maladaptive metacognitive beliefs contribute to the activation of an unhelpful, perseverative style of information processing in health-related stressful situations.

AIM

The aim of this study was to evaluate the relationship between metacognitions and emotional status, burden and coping strategies in ALS primary caregivers.

METHODS

A total of 70 couples of ALS patients and their caregivers consecutively seen in NEMO Clinical Centers, fifty in Messina and twenty in Milan, participated in the study.

Caregivers had to meet the following inclusion criteria: being the primary caregiver and having a negative history of disorders which could affect cognition and behaviour. Exclusion criteria were the presence of cognitive impairment and serious diseases and functional limitations.

Metacognitive beliefs and processes relevant to vulnerability and maintenance of emotional disorders were evaluated by the Metacognitions Questionnaire 30 (MCQ-30).

Anxiety was measured with the State-Trait Anxiety Inventory (STAI), a self-report questionnaire

Depressive symptoms were assessed with the Beck Depression Inventory II (BDI-II).

Caregivers' coping strategies, burden and needs were assessed with the following measurements:

- Brief COPE
- Caregiver Burden Inventory (CBI),
- Caregiver Needs Assessment (CNA)
- ALS Caregiver Needs and Burden Questionnaire (ALS CNB-Q)

Patients' physical status was evaluated with the Revised -ALS Functional Rating Scale (ALSFRS-R).

The study has been approved by the Ethical Committee of our Institution. Each participant signed a written informed consent.

RESULTS

The cohort consisted of 70 primary caregivers and related ALS patients. We included twenty-six male (37%) and forty-four female (63%) primary caregivers. The age ranged from 22 to 79 years (mean= 51.98; SD ± 15.54). The primary caregivers were 40 (57%) partners/spouses, 27 (39%) sons/daughters and 3 (4%) brothers/sisters. The mean educational level in years was 12.81 (SD ± 4.05). The highest educational level reached was grade-school diploma in 9 caregivers (13%), middle-school diploma in 12 (17,5%), high-school diploma in 31 (44, 9%), University degree in 17 (24,6%).

Sociodemographic and clinical characteristics of patients are showed in Table 1. Caregivers' Brief COPE and other measures' subscores are detailed in Table 2. MCQ-30 total score was positively related to state and trait anxiety (STAI_s and STAI_t), cognitive and somatic aspects of depression (BDI-II) and also caregiver burden (CBI and ALS CNB-Q).

Among the MCQ-30 different sub-scales, MCQ_NEG, MCQ_NC, and MCQ_POS showed the strongest correlations with all the above mentioned aspects and particularly with depressive symptoms and trait anxiety (Table 3).

Correlation between caregivers' metacognitions and coping strategies are showed in table 4. Correlation between caregivers' burden and patient's functional status, disease duration, time-frame of caregiving.

Caregivers' burden (CBI) was negatively related to ALSFRS- R total score with the strongest correlation with the subscore time dependence burden (CBI_TD) (Table 5).

CONCLUSIONS

1. In keeping with previous evidence a significant proportion of ALS caregivers experiences high level of anxiety. Although only 7% of our cases showed a high level of trait anxiety, 30% had a high level of state anxiety.
2. Only 10% of our cohort showed severe level of depression. This is reflected by our novel report of a trend towards higher scores in adaptive than in maladaptive coping strategies (Brief COPE subscores, table 2).
3. We confirmed previous evidence showing a high burden in this population with 20% of our cohort at risk of "burning out". The level of burden was negatively influenced by increased functional impairment and was not related to disease duration and time-frame of caregiving.
4. In ALS caregivers maladaptive coping strategies, such as behavioral disengagement, denial and venting, are positively associated with dysfunctional metacognitive beliefs as "positive beliefs about own perseverative", "negative beliefs about worry concerning uncontrollability and danger" and "need to control thoughts".

This study provides evidence that dysfunctional metacognitive beliefs might be predictive factors of higher ALS caregivers' state and trait anxiety, cognitive and somatic aspects of depression, burden and an increased utilization of maladaptive coping strategies. We suggest the importance to evaluate not only the patient's but also caregiver's psychological functioning in order to individuate metacognitive beliefs, emotional symptoms, resilience and vulnerability factors which could benefit of specific psychological therapy.

Table 1. Sociodemographic and clinical characteristics of patients

Age (mean ± SD), years	64.04 ± 9.96
Gender (n, percent)	
Male	26 (37%)
Female	44 (63%)
Onset phenotype (n, percent)	
Bulbar	24 (36.2%)
Spinal	46 (63.8%)
ALFRS-R (mean ± SD)	21.7 ± 10.7
Disease duration (mean ± SD), months	44.04 ± 42.6
Timeframe since care beginning (mean ± SD), months	28.8 ± 37.1
Hours of care provided per day (n, percent)	
24 hours	32 (46.4%)
12 hours night-time	2 (2.9%)
3 hours day-time	13 (18.8%)
4-6 hours day-time	15 (21.7%)
7-12 hours day-time	7 (10.1%)

Table 2. Caregivers' Brief COPE and other measures subscores

	Mean	± SD
BDI-II_COG	4.61	± 4.31
BDI-II_SOM-AFF	10.01	± 6.25
MCQ_POS	10.67	± 4.26
MCQ_NEG	11.47	± 3.33
MCQ_CC	11.43	± 4.70
MCQ_NC	11.73	± 3.16
MCQ_CSC	16.29	± 3.34
CBI_TD	11.94	± 6.26
CBI_D	7.91	± 5.07
CBI_S	3.44	± 3.31
CBI_E	1.48	± 2.04
CBI_P	5.71	± 4.94
CNA-EMO_SOC	16.06	± 6.66
CNA-D/NO_COM	17.77	± 5.14
CNA_COG	9.23	± 2.76
CNA_FIS	4.23	± 1.52
CNA_EMO	3.51	± 1.91
CNA_REL	9.27	± 3.66
CNA_SOC	6.29	± 2.32
CNA_SPIR	1.30	± 1.13
BRIEF_D	3.37	± 1.60
BRIEF_V	3.83	± 1.30
BRIEF_SD	4.50	± 1.77
BRIEF_AC	5.80	± 1.75
BRIEF_SU	2.13	± 0.54
BRIEF_UES	4.10	± 1.78
BRIEF_UIS	4.89	± 1.82
BRIEF_BD	2.73	± 1.06
BRIEF_PR	4.99	± 1.91
BRIEF_P	5.90	± 1.58
BRIEF_H	3.11	± 1.42
BRIEF_A	5.97	± 1.96
BRIEF_R	4.90	± 2.32
BRIEF_SB	3.84	± 1.38

Table 3. Correlation coefficients between metacognition and psychopathological symptoms and burden

	MCQ_P	MCQ_NEG	MCQ_CC	MCQ_NC	MCQ_CSC	MCQ30_TOT
STAI _s	0.224	0.375**	0.116	0.339**	0.166	0.389**
STAI _t	0.242*	0.542**	0.192	0.339**	-0.062	0.440**
BDI-II_Cog	0.171	0.550**	0.252*	0.236*	0.031	0.402**
BDI-II_SomAff	0.339**	0.571**	0.252*	0.203	0.049	0.445**
BDI-II_TOT	0.298*	0.609**	0.259*	0.244*	0.046	0.467**
CBI_TOT	0.338**	0.497**	0.213	0.367**	-0.028	0.456**
ALS_CNB_Q	0.353**	0.461**	0.232	0.379**	0.132	0.507**

Table 4. Correlation coefficients between metacognition and coping strategies

	MCQ_POS	MCQ_NEG	MCQ_CC	MCQ_NC	MCQ_CSC	MCQ_TOT
BRIEF_D	0,043	0,463**	0,079	0,194 **	0,080	0,233
BRIEF_V	0,232 **	0,460**	-0,009	0,170	0,191	0,321
BRIEF_BD	0,360 **	0,183	0,189	0,269	0,064	0,369**

**p<0.01

Table 5. Correlation coefficients between caregiver burden and psychological status, and patient level of impairment

	CBI_TD	CBI_S	CBI_F	CBI_D	CBI_E	CBI_TO	ALS_CNB_Q
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ALS_FR_S_R	-0.603**	-0.168	-0.190	-0.282*	0.028	-0.409**	-0.188
STAI _s	0.280*	0.501**	0.503**	0.361**	0.171	0.510**	0.500**
STAI _t	0.254*	0.613**	0.632**	0.414**	0.354**	0.578**	0.542**
BDI-II_Cog	0.387**	0.520**	0.528**	0.521**	0.252*	0.603**	0.579**
BDI-II_SomAff	0.313**	0.555**	0.668**	0.494**	0.284*	0.599**	0.639**
BDI-II_TOT	0.360**	0.583**	0.665**	0.545**	0.318**	0.649**	0.675**

* p<0.05; **p<0.01