The role of metacognitive beliefs on anxiety and depression among Amyotrophic Lateral Sclerosis caregivers

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Abstract

Previous studies have investigated the role of metacognitive beliefs in patients with a chronic medical condition and their caregivers. However, there is still a paucity of studies that have examined dysfunctional metacognitive beliefs and their relationships with anxiety and depression in Amyotrophic Lateral Sclerosis caregivers (ALS). This study aimed at examining the role of gender and dysfunctional metacognitive beliefs on anxiety and depression in ALS patients’ caregivers. The study was conducted on a group of 70 caregivers (26 males and 44 females, mean age = 51.98, SD = 15.54) of ALS patients referred to the NEMO Clinical Centers of Messina and Milano and a matched control group drawn from the MCQ-30 Italian normative database. The Metacognitions Questionnaire-30 (MCQ-30), the State-Trait Anxiety Inventory (STAI), and the Beck Depression Inventory-II (BDI-II) were administered. Results showed a significant multivariate effect of gender with females scoring higher than males on anxiety and depression. Dysfunctional metacognitive beliefs had a significant multivariate effect on anxiety and depression. Finally, there were no significant differences between ALS patients and caregivers.
caregivers and healthy subjects for any metacognitive factors. Further investigations might clarify the potential role of metacognitions as vulnerability factors to the development of emotional disorders.

**Keywords:** Metacognition; Gender; ALS caregiver; Neurological diseases; Cross-sectional study.
1. Introduction

Amyotrophic Lateral Sclerosis (ALS), the most common form of motor neuron pathologies, is a neurodegenerative disease characterized by degeneration of both the lower (LMNs) and upper motor neurons (UMNs), progressively leading to weakness of voluntary movement muscles (Soriani & Desnuelle, 2017). ALS is characterized by heterogeneous patterns of symptoms, involving falls, limb weakness, communication difficulties, behavioral disturbances (Hogden, Foley, Henderson, James, & Aoun, 2017) as well as changes in mood (Carvalho, de Almeida, Lorega, Barata, Ferreira, de Brito-Marques et al., 2016) and cognition (Beeldman, Raaphorst, Klein Twennar, de Visser, Schmand, & de Haan, 2016).

Results from several studies have shown the experience of high levels of caregiver burden in the context of neurological diseases (Tramonti, Bonfiglio, Bongioanni, Belviso, Fanciullacci, Rossi et al., 2018). The caregivers’ burden is strongly correlated to their level of depression and quality of life (Chiò, Gauthier, Calvo, Ghiglione, & Mutani, 2005). Behavioral changes in ALS patients, such as impulsivity and caregiver stress, have a greater impact on caregiver burden than the level of physical disability (Lillo, Mioshi, & Hodges, 2012). However, the presence of negative emotions in the relationship between clinicians, patients, and their caregivers could be difficult to recognize (Dicè, Aurichhio, Boursier, De Luca Picione, Santamaria, Salerno et al., 2018). Feelings of inadequacy stemming from caregiving and experiences of daily distress can affect the caregiver’s well-being (Dicè & Zoena, 2017).

In this regard, it could be reasonable to hypothesize the emotional-somatic impact of ALS caregiving. Results of a cross-sectional study among 40 ALS caregivers have shown that burden, depression, and anxiety were jointly related (Pagnini, Rossi, Lunetta, Banfi, Castelnuovo, Corbo et al., 2010). Further studies adopting qualitative approaches have pointed out that the meaning-making process underlying the traumatic experience of caregiving might influence the subjective well-being of the caregiver (Freda & Martino, 2015). Hence, psychosocial factors have a key role in determining psychological well-being in caregivers of people with ALS. Few studies have deeply investigated the role of psychological variables to predict caregiver burden in neurological diseases (Goldstein, Atkins, Landau, Brown, & Leigh, 2006; Wolfs, Kessels, Severens, Brouwer, de Vugt, Verhey et al., 2012; Rainone, Chiodi, Lanzillo, Magri, Napolitano, Morra et al., 2016). In addition, it remains unclear the role of gender as a
potential predictor of caregiver burden and distress. Previous studies have often produced contradictory results depending on many variables, such as psychological functioning, patient's disease, and clinical setting (Gilbar, 1999; Costa-Requena, Cristófol, & Cañete, 2011; Quattropani, Lenzo, Baio, Bordino, Germanà, Grasso et al., 2017; Lenzo, Sardella, Martino, & Quattropani, 2020). However, it was recently suggested that gender differences related to mental health might play an important role in the development of anxiety and depression (Lenzo, Toffle, Tripodi, & Quattropani, 2016).

In this perspective, Wells & Matthews (1996) have demonstrated the central role of dysfunctional metacognitive beliefs for the development and maintenance of anxiety and depression. Metacognition is defined as “the aspect of information processing that monitors, interprets, evaluates and regulates the contents and processes of its organization” (Wells & Purdon, 1999) and represents a new field of research, originally investigated in psychiatric samples (Cotter, Yung, Carney, & Drake, 2017; Sellers, Varese, Wells, & Morrison, 2017).

An important approach is the Self-Regulatory Executive Function (S-REF) model proposed by Wells and Matthews (1996). A central principle of the S-REF model is that it accounts for those transdiagnostic processes involved in emotional disorders. Thus, the focus is not on symptoms or diagnosis but on the dysfunctional metacognitive beliefs and emotional self-regulation strategies behind. In this context, the vulnerability to emotional disorders has been specifically associated with a specific relevant construct of Wells’ metacognitive theory, which is named Cognitive Attentional Syndrome (CAS) (Wells, 2000, 2009). The CAS is defined as a series of psychological processes derived from metacognitive beliefs, either positive or negative, and includes repetitive negative thinking (i.e. worry and rumination), threat monitoring, and associated unhelpful behavioral and cognitive strategies (Kowalski, Wypych, Marchewka, & Dragan, 2019). More specifically, strategies as pathological worry, rumination, and threat monitoring define positive beliefs. Conversely, beliefs about the danger and uncontrollability of certain thoughts characterize negative beliefs. Examples of positive beliefs are “worrying helps me to cope” or “worrying helps me to solve problems”. Examples of negative beliefs are “my worrying is dangerous for me” and “my worrying could make me go mad”. According to Well’s metacognitive theory, dysfunctional metacognitive beliefs appear as predictive factors involved in the development of several psychological symptoms (Yilmaz, Gençöz, & Wells, 2011).
growing interest on metacognition is well documented, as metacognitive beliefs have been recently associated with the onset and maintenance of a wide range of psychopathological disorders including schizophrenia (Davies & Greenwood, 2018), post-traumatic stress disorder (Leonhardt, Lysaker, Vohs, James, & Davis, 2018), anxiety disorder (Sadeghi, Mokhber, Mahmoudi, Asgharipour, & Seyfi, 2015) and major depression (Quiles, Prouteau, & Verdoux, 2015).

The putative role of metacognitive beliefs has been also recently investigated in clinical neurological samples (Rosen, Alcantar, Zakrzewski, Shimamra, Neuhaus, & Miller, 2014; Brown & Fernie, 2015; Al Banna, Redha, Abdulla, Nair, & Donnellan, 2016; Donnellan, Al Banna, Redha, Al Sharoqi, Al-Jishi, Bakhiet et al., 2016; Quattropani, Lenzo, & Filastro, 2018). Here, the association between metacognition and ALS represents a recent topic of interest, due to its putative impact on several outcomes.

Beyond the presence of many health professionals involved in the multidisciplinary management of the disease, patients with ALS become increasingly dependent on the support and care of their partner and relatives (Creemers, de Morée, Veldink, Nollet, van den Berg, & Beelen, 2016). In this perspective, the primary caregiver plays a crucial role in assisting the patient in carrying out activities of daily living, which exposes him/her to a high risk of psychological distress and emotional burden. For this reason, an increased number of studies have deeply focused on the psychological well-being of ALS patient’s caregivers, highlighting the crucial need for considering even the psychological impact of the disease (Burke, Galvin, Pinto-Grau, Lonergan, Madden, Mays et al., 2017).

Hence, metacognitions have been recently found to modulate emotional burden and coping strategies in dyad ASL patients and caregivers (Quattropani, La Foresta, Russo, Faraone, Pistorino, Lenzo et al., 2018). However, a peculiar investigation of the metacognitive patterns of ALS caregivers, regardless of dyadic caregiver-patients relationship, remains unclear.

2. Aims and hypothesis

The present study aimed at examining the role of gender and dysfunctional metacognitive beliefs on anxiety and depression in ALS patients’ caregivers. We hypothesized a significant effect of gender and dysfunctional metacognitive beliefs on both anxiety and depression. Previous studies involving both clinical and non-clinical samples have
already shown these relationships, even though no data is still available on ALS caregivers. The second aim of this study was to compare ALS patients’ caregivers and healthy controls for the dysfunctional metacognitive beliefs. We hypothesized the absence of significant differences between the two samples since metacognitions might be considered a vulnerability factor for the development and maintenance of emotional disorders.

3. Materials and Methods

3.1. Participants

This study involved 70 caregivers of ALS patients screened according to El-Escorial criteria who visited the NEMO Clinical Centers of Messina and Milano. Data about the patient’s disease duration and functional status were also collected with the ALS Functional Rating Scale-Revised (ALSFRS-R; Cedarbaum, Stambler, Malta, Fuller, Hilt, Thurmond et al., 1999). The primary caregiver was the person indicated by the patient as the ‘main informal caregiver’. All caregivers were recruited from the Nemo Clinical Centers. Paid caregivers were excluded from the study. Researchers informed ALS caregivers that data would have been treated confidentially and only for research purposes. Before the beginning of the study, all participants gave written consent. Exclusion criteria for ALS caregivers included a positive anamnesis for schizophrenia or any psychiatric disorder included in the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatry Association, 2013).

The control sample was randomly drawn from the MCQ-30 Italian normative database (N = 306) after applying constraints to achieve group-wise matching on average chronological age. The mean age of healthy group was [years ± standard deviation (SD)] 51.5 ± 14.8. The matching process was conducted entirely independently of the study hypotheses. A between t-test showed no significant difference in the mean age of participants of the caregiver group and healthy group, t (-.206), p = .837. In addition, there were no significant between-group differences in the distribution of gender or marital status.

The study was approved by the Ethical Committee of the University of Messina (n. 53/16). The study was conducted in accordance with the 1964 Declaration of Helsinki and its later amendments and written informed consent was obtained from all the participants.
3.2. Instruments

3.2.1. Dysfunctional metacognitive beliefs

The Metacognitions Questionnaire-30 (MCQ-30; Wells & Cartwright-Hatton, 2004) is a 30 item self-report questionnaire, which measures a range of metacognitive beliefs and processes relevant to vulnerability and maintenance of emotional disorders. The items are rated on a 4-point Likert scale from 1 (‘do not agree’) to 4 (‘completely agree’). The items are also clustered into five subscales and a total score. The subscales are namely positive beliefs of worry, negative beliefs about worry and danger, cognitive confidence, beliefs about the need to control thoughts, cognitive self-consciousness, as in the original version (Cartwright-Hatton & Wells, 1997).

Factorial analysis has shown the presence of five factors: positive beliefs about worry, which measures the extent to which a person thinks that perseverative thinking is useful (Positive beliefs about worry, POS); negative beliefs about worry concerning uncontrollability and danger, which assess the extent to which a person thinks that perseverative thinking is uncontrollable and dangerous (Negative beliefs about uncontrollability and danger, NEG); cognitive confidence, which measures confidence in attention and memory (Cognitive confidence, CC); beliefs about the need to control thoughts, which assess the extent to which a person believes that certain types of thoughts need to be suppressed (Need to control thoughts, NC); cognitive self-consciousness, which measures the tendency to monitor one’s own thoughts and focus attention inward (Cognitive self-consciousness, CSC). All items refer to general ideas and a high score on each factor is considered as dysfunctional. The MCQ-30 is a brief, reliable, and valid self-reporting measure of metacognitions (Cartwright-Hatton & Wells, 1997; Spada, Nikčević, Moneta, & Wells, 2008). In this study, a validated Italian version of the MCQ-30 was used to assess metacognitive beliefs (Quattropani, Lenzo, Mucciardi, & Toffle, 2015). Results of the Italian version of MCQ-30 indicated, as in the original version, direct correlations between metacognitive factors (except for CSC) and state and trait anxiety, pathological worry, and obsessive-compulsive symptoms. The degree of reliability in the present sample was good, with Cronbach’s α of .85 for POS, .79 for NEG, .86 for CC, .73 for NC, .78 for CSC, and .82 for the total score of MCQ-30.
3.2.2. Anxiety

Anxiety symptoms have been explored by the State-Trait Anxiety Inventory (STAI; Spielberger, 1983; Pedrabissi & Santinello, 1989) which is a self-reported questionnaire that measures state and trait anxiety. Every scale consists of 20 items, rated on a 4-point Likert scale. The degree of reliability of the two factors in the present sample was good, with Cronbach’s $\alpha$ of .95 for the X1 form subscale and .92 for the X2 form.

3.2.3. Depression

Depressive symptoms have been also assessed by the Beck Depression Inventory-II (BDI-II; Beck, Steer, & Brown, 1996; Ghisi, Flebus, Montano, Sanavio, & Sica, 2006) which is a self-reported questionnaire that allows assessing the severity of depressive symptoms. It consists of 21 items and can be divided into two subscales evaluating both somatic and cognitive aspects of depression respectively. The degree of reliability of the two factors and the total score in the present sample was good, with Cronbach’s $\alpha$ of .89 for the somatic subscale, .83 for the cognitive subscale, and .92 for the total score.

4. Data analysis

Data shows a good range of variance and there were not unvaried outliers for STAI-X1 and X2, BDI, and MCQ-30. Furthermore, skewness and kurtosis values are less of $\left|1.00\right|$ for each scale of STAI, BDI, and MCQ-30.

Statistical analysis was carried out using means and SDs, multivariate analysis of variance (MANOVA), and test post-doc. Subsequently, an identical MANCOVA was performed, controlling for participant age, months duration of caregiving for the patient with ALS, dysfunctional metacognitive beliefs. The levels of statistical significance were set at $p < .05$ and $p < .01$. Comparisons between ALS caregivers and control groups were performed with Student’s $t$-test for independent samples to compare participant age and metacognitive dysfunctional beliefs. The Bonferroni correction was applied to address type 1 errors.
5. Results

5.1. Sample Characteristics

The sociodemographic characteristics of the studied sample are shown in Table 1. The sample consisted of twenty-six (37%) males and forty-four (63%) females. The age ranged from 22 to 79 years ($M = 51.98; SD = 15.54$). The level of education in years was $12.81 (SD = 4.05)$. The caregivers were 40 partners/spouses, 27 sons/daughters, and 3 brothers/sisters.

Table 1 - Sociodemographic characteristics of ALS caregivers

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N (%)</th>
<th>M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td></td>
<td>51.98 (15.54)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>26 (37)</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>44 (63)</td>
<td></td>
</tr>
<tr>
<td>Education (years)</td>
<td></td>
<td>12.81 (4.05)</td>
</tr>
<tr>
<td>Relation to patient</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Partner/Spouse</td>
<td>40 (57)</td>
<td></td>
</tr>
<tr>
<td>Son/Daughter</td>
<td>27 (39)</td>
<td></td>
</tr>
<tr>
<td>Brother/Sister</td>
<td>3 (4)</td>
<td></td>
</tr>
<tr>
<td>Time since care beginning (in months)</td>
<td></td>
<td>28.8 (37.10)</td>
</tr>
<tr>
<td>Hours of care provided per day</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 hours day-time</td>
<td>13 (18.8)</td>
<td></td>
</tr>
<tr>
<td>4-6 hours day-time</td>
<td>15 (21.7)</td>
<td></td>
</tr>
<tr>
<td>7-12 hours day-time</td>
<td>7 (10.1)</td>
<td></td>
</tr>
<tr>
<td>12 hours night-time</td>
<td>2 (2.9)</td>
<td></td>
</tr>
<tr>
<td>24 hours</td>
<td>33 (46.4)</td>
<td></td>
</tr>
<tr>
<td>Patient ALSFRS-R score</td>
<td></td>
<td>21.69 (1.69)</td>
</tr>
<tr>
<td>Time since diagnosis in months</td>
<td></td>
<td>44.04 (42.59)</td>
</tr>
</tbody>
</table>
5.2. Manova Analysis

A MANOVA was carried out with the two subscales and the total score of BDI, and state-trait anxiety as the dependent variables and the gender as the independent variable (Tab. 2). There was a significant multivariate main effect of gender [Wilks’ Lambda = .760, \( F(4, 65) = 5.118, p = .001, n_p^2 = .240 \)] with female scoring significantly higher than male on somatic aspects of depression, \( F(1, 68) = 5.916, p = .018, n_p^2 = .080 \), cognitive symptoms of depression, \( F(1, 68) = 4.481, p = .038, n_p^2 = .062 \), global depressive symptoms, \( F(1, 68) = 6.387, p = .014, n_p^2 = .086 \), state anxiety, \( F(1, 68) = 10.332, p = .002, n_p^2 = .132 \), and trait anxiety \( F(1, 68) = 18.425, p = .0001, n_p^2 = .213 \).

Table 2 - Descriptive statistics and MANOVA across gender

<table>
<thead>
<tr>
<th>Variable</th>
<th>Male M (SD)</th>
<th>Female M (SD)</th>
<th>F</th>
<th>p</th>
<th>( n_p^2 )</th>
</tr>
</thead>
<tbody>
<tr>
<td>STAI X1</td>
<td>45.50 (8.54)</td>
<td>54.77 (13.14)</td>
<td>10.332</td>
<td>.002</td>
<td>.132</td>
</tr>
<tr>
<td>STAI X2</td>
<td>39.30 (11.07)</td>
<td>49.73 (9.00)</td>
<td>18.425</td>
<td>.000</td>
<td>.213</td>
</tr>
<tr>
<td>Som_Depr</td>
<td>7.73 (5.86)</td>
<td>11.36 (6.14)</td>
<td>5.916</td>
<td>.018</td>
<td>.080</td>
</tr>
<tr>
<td>Cogn_Depr</td>
<td>3.23 (3.91)</td>
<td>5.43 (4.36)</td>
<td>4.481</td>
<td>.038</td>
<td>.062</td>
</tr>
<tr>
<td>BDI-II</td>
<td>10.96 (8.66)</td>
<td>16.80 (9.70)</td>
<td>6.387</td>
<td>.014</td>
<td>.086</td>
</tr>
</tbody>
</table>

Note: STAI-X1 = State-Trait Anxiety Inventory – X1 Form; STAI-X2 = State-Trait Anxiety Inventory – X2 Form; Som_Depr = Somatic symptoms factor of Beck Depression Inventory-II; Cogn_Depr = Cognitive symptoms factor of Beck Depression Inventory-II; BDI-II = Global score of Beck Depression Inventory-II.

5.3. Mancova Analysis

Subsequently, an identical MANCOVA was performed, controlling for participant age, months duration of care giving for the patient with ALS, dysfunctional metacognitive beliefs. Results of MANCOVA showed that the differences between male and female gender groups persist even after these covariates has been controlled for (Tab. 3). Thus, significant multivariate effects were found for gender [Wilks’ Lambda = .755, \( F(4, 55) = 4.454, p = .003, n_p^2 = .245 \)] and for the dysfunctional metacognitive beliefs [Wilks’ Lambda = .231, \( F(4, 55) = 4.140, p = .005, n_p^2 = .231 \)], but not for the other the covariates, as participant age [Wilks’ Lambda = .013, \( F(4, 55) = .181, p = .947, n_p^2 = .013 \)], months duration of care giving for the patient with ALS [Wilks’ Lambda = .033, \( F(4, 55) = .464, p = .762, n_p^2 = .013 \)].
Table 3 - Descriptive statistics and MANCOVA

<table>
<thead>
<tr>
<th>Variable</th>
<th>Wilks’ Lambda</th>
<th>F</th>
<th>p</th>
<th>$n_p^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>.755</td>
<td>4.454</td>
<td>.003</td>
<td>.245</td>
</tr>
<tr>
<td>Age</td>
<td>.013</td>
<td>.181</td>
<td>.947</td>
<td>.013</td>
</tr>
<tr>
<td>Months Duration</td>
<td>.033</td>
<td>.464</td>
<td>.762</td>
<td>.013</td>
</tr>
</tbody>
</table>

Note: Months duration = months duration of care giving for the patient with ALS.

5.4. Comparisons between ALS caregivers and healthy control subjects for dysfunctional metacognitive beliefs

There were no significant differences (with Bonferroni correction for six comparisons $p = .008$) between ALS caregivers group and healthy control group for any metacognitive factor (see Tab. 4).

Table 4 - t-test between ALS caregivers group and healthy control group for MCQ-30

<table>
<thead>
<tr>
<th>Variable</th>
<th>Caregivers $M (SD)$</th>
<th>Controls $M (SD)$</th>
<th>$t$</th>
<th>$p^*$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive Confidence</td>
<td>11.43 (4.69)</td>
<td>10.13 (3.39)</td>
<td>-2.064</td>
<td>.040</td>
</tr>
<tr>
<td>Positive beliefs about worry</td>
<td>10.67 (4.25)</td>
<td>10.19 (4.96)</td>
<td>-.738</td>
<td>.461</td>
</tr>
<tr>
<td>Negative beliefs about worry</td>
<td>11.47 (3.32)</td>
<td>11.77 (4.59)</td>
<td>.540</td>
<td>.589</td>
</tr>
<tr>
<td>Cognitive Self consciousness</td>
<td>16.29 (3.33)</td>
<td>16.83 (3.60)</td>
<td>1.084</td>
<td>.280</td>
</tr>
<tr>
<td>Need to control thoughts</td>
<td>11.73 (3.15)</td>
<td>12.19 (3.90)</td>
<td>.914</td>
<td>.362</td>
</tr>
</tbody>
</table>

*with Bonferroni correction for six comparisons the new significance was $p = .008$

6. Discussion

Few studies have investigated the impact of metacognitive beliefs on ALS patient’s caregivers. The current cross-sectional study aimed at exploring metacognitive beliefs in ALS patients’ caregivers and their putative involvement in modulating anxiety levels and depressive symptoms. The main evidence was that ALS caregivers compared to healthy controls (randomly drawn from the MCQ-30 Italian normative database) did not differ for any dysfunctional metacognitive factor measured by MCQ-30. This result suggests that dysfunctional metacognitive beliefs are
significantly associated with emotional and psychological distress in ALS patients’ caregivers, regardless of the dyadic patient-caregiver relationship.

The evaluation of metacognitive beliefs has been flexibly applied in multiple clinical and non-clinical samples (Lenzo, Maisano, Garipoli, Aragona, Filastro, Verrastro et al., 2020). Metacognitive beliefs, in fact, represent multidimensional factors, whose role has been investigated in the development of several psychopathological conditions (Sun, Zhu, & So, 2017) as well as in the management of chronic pathologies (Quattropani, Lenzo, Mucciardi, & Toffle, 2016; Quattropani, Lenzo, & Filastro, 2017; Ziadni, Sturgeon, & Damall, 2017; Heffer-Rahn & Fisher, 2018). These studies have investigated the role of dysfunctional metacognitive beliefs as potential vulnerability factors in predicting the development of psychological symptoms (Wells & Carter, 2001).

The importance of metacognition in the context of mental and physical health seems precisely associated with the self-regulatory executive function (S-REF) model, according to which metacognitive beliefs contribute to modulate emotional responses (Wells & Matthews, 1996). In light of this perspective, an increasing number of researches has shown that family members who provide care to relatives with chronic or disabling conditions are themselves at risk of experiencing distress and emotional burden (Jansen, Harder, Haahr, Lyse, Pedersen, Trauelsen et al., 2015).

The caregiver burden is generally defined as the impact of adopting the caregiving role on caregiver’s emotional and physical health, social life, and financial status (Zarit, Todd, & Zarit, 1986). Relevant risk factors for caregiver burden usually include low educational level and residing with the patient to care. Depression, social isolation, a higher number of hours spent caregiving, and lack of choice in being a caregiver are other common risk factors (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014). In addition, women appear to be more at risk of developing caregiver burden than men (Berg & Woods, 2009). This increased female vulnerability was found for example among female caregivers of terminally ill cancer patients (Schrank, Ebert-Vogel, Amering, Masel, Neubauer, Watzke et al., 2015), dementia affected patients (Gallicchio, Siddiqi, Langenberg, & Baumgarten, 2002; Etters, Goodall, & Harrison, 2008) and psychiatric patients (Awad & Voruganti, 2008). ALS represents the most common form of motor neuron disease and the third most common neurodegenerative disease (Soriani & Desnuelle, 2009). Since its poor prognosis and the progressive severity of impairments involving breathing, swallowing, and speech functions,
managing ALS can have a strong impact on both patient’s and caregiver’s quality of life (Boerner & Mock, 2012).

ALS patients’ caregivers are often exposed to high risk of developing emotional burden, particularly in relation to the degree of patient’s behavioral and physical impairment (de Wit, Bakker, van Groenestijn, van den Berg, Schröder, Visser-Meily et al., 2018). In our studied sample, the majority of evaluated caregivers were women: this is consistent with literature evidence confirming the female gender as the most vulnerable; furthermore, the presence of female caregivers is not unusual since ALS is more prevalent in men (McCombe & Henderson, 2010). Our study has also shown that female caregivers have shown higher levels of anxiety and depression when compared to men. This evidence is consistent with previous findings that highlighted a higher probability of psychological burden in female caregivers involved in chronic assistance compared to men (Goldstein, Concato, Fried, Kasl, Johnson-Hurzeler, & Bradley, 2004; Sharma, Chakrabarti, & Grover, 2016). Caregiving in ALS, due to patient’s rapid decline in physical functioning, constantly requires both physical and emotional adjustments: given that women are more easily involved in other family activities, this extra effort could lead to reduced social participation and increased negative emotions (Tramonti, Bongioanni, Leotta, Puppi, & Rossi, 2015).

We acknowledge as limitations of the study the cross-sectional design as well as that the metacognitive and psychological evaluation did not involve the dyadic patient-caregiver relationship, as previously (Quattropani, La Foresta et al., 2018). However, to our knowledge, this is the first attempt to explore metacognition as an independent stable factor involved in managing the emotional burden among ALS patient’s caregivers. If confirmed by future research, the results of this study could have implications in clinical practice. Given the relationship between metacognitions and negative emotion, a supportive and time-limited group intervention could help in fostering mentalization for ALS patients’ caregivers (Lenzo, Gargano, Mucciardi, Lo Verso, & Quattropani, 2014; Rugnone, Traina, Lenzo, Venturella, Ruvolo, & Falgares, 2017; Esposito, Marano, & Freda, 2018). At the same time, auxiliary therapies should be considered useful to support psychological interventions (Dicè, Santaniello, Gerardi, Paoletti, Valerio, Freda et al., 2018).

Future studies may be needed in order to explore the association between metacognition and a wider range of negative emotions among ALS patients ‘caregivers. Moreover, longitudinal observations could better describe the
impact of caregivers’ metacognitive beliefs in relation to the duration of the disease and the progressive greater difficulty in care.

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