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# The effect of social support on the emotional well-being of people with amyotrophic lateral sclerosis: Exploring the mediating role of spirituality

Anne Fernandez, PH.D.[1], Léo Guenegou[2], Philippe Corcia, M.D., PH.D.[3] and Nathalie Bailly, PH.D.[2]

[1]Centre de Coordination des Centres de Référence Maladies Rares (CRMR) SLA, CHRU de Tours, France; [2]Laboratoire EA 2114 PAVeA (Psychologie des Ages de la Vie et Adaptation), Département de Psychologie, Université de Tours, France and [3]Centre de Coordination des Centres de Référence Maladies Rares (CRMR) SLA, CHRU de Tours, INSERM U1253, France

**Original Article**

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**Corresponding author:** Anne Fernandez; Email: a.fernandez@chu-tours.fr

## Abstract

**Objectives.** Amyotrophic lateral sclerosis (ALS) is a progressive neurodegenerative disease that, so far, is considered always fatal. Treatments mainly consist in increasing survival and aim to improve the quality of life of people with ALS (pwALS). Social support and spirituality have been shown to play a key role in pwALS' quality of life. Our study explored it in depth by investigating the underlying mechanisms linking social support, spirituality, and emotional well-being.

**Methods.** Thirty-six pwALS underwent a battery of tests evaluating emotional well-being (emotional well-being scale of the 40-item Amyotrophic Lateral Sclerosis Assessment Questionnaire), social support (6-item Social Support Questionnaire), and spiritual well-being (12-item Functional Assessment of Chronic Illness Therapy – Spiritual well-being). Our recruitment was web-based through the FILSLAN and the ARSLA websites as well as through Facebook® advertisements (ALS groups). Data were analyzed by Pearson correlation analysis and Process macro was used in an SPSS program to analyze the mediator variable effect.

**Results.** Availability of social support, spiritual well-being, and 2 of its dimensions, i.e., meaning and peace, were positively correlated with emotional well-being. The mediational analyses showed that spiritual well-being, meaning, and peace act as mediators in the association between availability of social support and good emotional well-being.

**Significance of results.** Availability of social support and spirituality are essential for the emotional well-being of pwALS. Spirituality as a mediator between availability of social support and emotional well-being appears as real novel finding which could be explored further. Spiritual well-being, meaning, and peace appear as coping resources for pwALS. We provide practical guidance for professionals working with pwALS.

## Introduction

Amyotrophic lateral sclerosis (ALS) is a progressive devastating neurodegenerative disease, characterized by the degeneration of both the upper and lower motor neurons which leads to an inexorable increase of weakness and paralysis of voluntary muscles, and finally to death, classically by respiratory insufficiency. On average, people with ALS (pwALS) survive 3–5 years after the first symptoms (Hardiman et al. 2017; Hartzfeld et al. 2015; Rosa Silva et al. 2020). This disease is considered always fatal, and its prognosis has been improved by clinical multidisciplinary consultations monitoring both medical aspects of the disease and the quality of life which spheres are all drastically shattered (Fisher et al. 2019; Van den Berg et al. 2005). ALS affects individuals' feeling of hope, personal activities, employment, and social life. Thus, physical health, psychological state, independence, and social relationships are deeply impacted.

Surprisingly, functional disability is less detrimental in determining well-being and quality of life in individuals with ALS than psychosocial factors (Chiò et al. 2015; Couratier et al. 2016; McLeod and Clarke 2007). Over the last 3 decades, several studies have shown strong association between social support and well-being, quality of life, and levels of self-esteem. It also appears to be protective against depression (Goldstein et al. 2006; McLeod and Clarke 2007). In their systematic review, Fisher et al. aimed to identify predictors of emotional distress in pwALS, among demographic factors, clinical characteristics, treatments, and psychological predictors, and only social support played a consistent role. Results highlighted that lower social support

was the only factor that consistently predicted anxiety and depression in pwALS (Fisher et al. 2019).

Social support refers to the various types of assistance from a social network (e.g., relatives, friends, colleagues, and significant others), which may be formal and/or informal, including emotional, physical, and informational support (Langford et al. 1997). Research suggests it plays an important role in health outcomes (Bryson and Bogart 2020; Jenks Kettmann and Altmaier 2008; Vrabec 1997). According to Schaefer and Moos (1998), social support fosters a more favorable appraisal of the event and more effective coping strategies.

Other support factors such as spiritual domain have been shown to be particularly striking to consider in this very special condition that is having to face an incurable illness (O'Brien and Clark 2015). Even if, compared to social support, fewer studies dedicated to individuals with ALS have considered these variables, Pagnini et al. have highlighted a direct link between spirituality issues and quality of life and severity of mood disturbance among sporadic ALS patients (Pagnini et al. 2011). Gonçalves et al. have also underlined in their literature review the role played by spirituality in quality of life among caregivers and pwALS (Gonçalves et al. 2022). As shown by O'Brien and Clark, using a qualitative methodology by collecting narratives written by pwALS/MND, spirituality impacts the quality of life providing a source of comfort and serenity (O'Brien and Clark 2015). Because spiritual beliefs can help alleviate anxiety and depressive disorders and even provide resources for coping with illness, spirituality beliefs and existential issues have been acknowledged to improve quality of life as end-of-life approaches (Cuniah et al. 2023; Delgado-Guay 2014). Indeed, a large body of literature indicates that spirituality and religious belief are factors in personal resilience and can moderate stress and health (Captari et al. 2022; Pereira et al. 2019; Reutter and Bigatti 2014).

Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred (Puchalski et al. 2009). Numerous studies have shown the positive relationship between spirituality and quality of life among patients living with life-threatening and chronic diseases (Abu et al. 2018; Büssing 2010). Spirituality can reduce the symptoms of illness and bring hope, comfort, and value to one's experience (Balboni et al. 2007; Stoltzfus and Green 2013), in turn improving individual's quality of life especially when faced with life-threatening illnesses such as cancer (Yilmaz and Cengiz 2019).

A positive association between social support and spirituality was found and revealed that social support can promote spirituality and life adaptation (Ciria-Suarez et al. 2021). Thus, we can put forward a mediating role of spirituality in the relationship between social support and emotional well-being. The theoretical framework of this hypothesis is the social cognitive processing model developed to better understand how benefit finding is derived from traumatic events such as cancer (Lepore and Kernan 2009). This model explains the interplay between social and cognitive factors in producing positive outcomes, benefit finding, and personal growth in illness. It emphasizes the role of social relationships in achieving positive life outcomes. Being integrated into society provides people with opportunities for social exchanges that can bring direct benefits, such as hope, positive affect, and compassion, give meaning to life and a sense of belonging. They remind patients that despite the disease, they remain the same person still needed and loved and may enhance their self-esteem. In addition, social connections influence cognitive adoption processes such as assimilation and accommodation. Giving new perception, new ways to appraise a stressor, they help patients to actively reframe their own situation and lead them to perceive positive information, thereby fostering assimilation. Social network members can also play a role in the accommodation process by changing their beliefs and expectations, introducing to new beliefs systems dealing with existential questions, religion, and meaning of life. Accordingly, spirituality appears as the result of a cognitive processing. Thus, it can be viewed as a coping resource that provides positive reappraisal for facing disease and make people more psychologically resilient in response to traumatic events (McEwen 1998).

Social support and spirituality are thus important factors for adjustment and quality of life in pwALS, but so far, to the best of our knowledge, only direct links have been studied. To enhance our understanding of these associations, we set out to explore them in depth by investigating the underlying mechanisms behind the links between social support, spirituality, and emotional well-being in individuals with ALS. Based on the above, it is expected that (1) social support and spirituality will be associated with emotional well-being and (2) spirituality will mediate the relationship between social support and emotional well-being.

## Methods

### Participants and procedure

We developed an online open survey through a data collection software program (SPHINX®).

We recruited participants via a link to the online survey and through social networks such as ALS groups on Facebook®. Social media posts from the FILSLAN (French rare diseases Healthcare Network: Amyotrophic Lateral Sclerosis and rare motor neuron diseases) and ARSLA (French Association for Research on ALS) describing the study and providing a link to the online survey were created to support enrollment. The survey was made available from June to August 2022. Before proceeding, all volunteers who participated in the study gave their consent and were guaranteed anonymity and confidentiality.

The study was approved by the local research ethics committee (n° CER-TP 2022-02-03).

French participants self-reported as pwALS who had access to the internet completed a 25-min questionnaire. Estimates for survey completion time were generated from the experience of the survey development team.

We received complete surveys from 36 participants.

### Measures

The following sociodemographic data were collected: age at inclusion in the study, gender, marital status, occupational status, and geographic area (urban, suburban, rural). Participants were also asked to answer questions related to their disease including duration since the announcement of the disease at inclusion, site of ALS, and availability of home assistance.

#### Emotional well-being

Emotional well-being was assessed using the emotional well-being scale of the 40-item Amyotrophic Lateral Sclerosis Assessment Questionnaire (Jenkinson et al. 1999) which contains 40 items incorporated in 5 scales: eating and drinking (3 items), communication (7 items), activities of daily living/independence (10 items), mobility (10 items), and emotional well-being (10 items). Respondents are asked to answer on a 5-point Likert-type scale

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ranging from Never "0" to Always/cannot do at all "4," according to how true each item statement has been over the past 2 weeks. Scores on each scale are then transformed to have a range from 0 (indicating the best health status) through to 100 (indicating the worst health status). The items of emotional well-being scale addresses various emotional problems, such as feeling lonely, bored, depressed, feeling embarrassed in social situations, and feeling worried about future disease course. In our study, the internal reliability of the emotional well-being scale was high ($\alpha = 0.92$).

### *Social support*

Social support was measured using the short version of Sarason's 6-item Social Support Questionnaire (Bruchon-Schweitzer et al. 2003; Sarason et al. 1983, 1987). It is a bifactorial questionnaire which measures 2 dimensions of social support: availability and satisfaction. The level and quality of self-perceived social support is evaluated using 6 items. For each item, respondents determine first how many people they can rely on (0–9 people maximum), then their satisfaction with this support on a 6-point Likert scale (from 1 "Very dissatisfied" to 6 "Very satisfied"). Two scores are calculated. The availability score ranges from 0 to 54, the satisfaction score from 6 to 36. A high score on the 2 dimensions indicates a high self-perceived social support. In our study, the internal reliability of the scale was high ($\alpha = 0.94$).

### *Spirituality*

The 12-item Functional Assessment of Chronic Illness Therapy – Spiritual well-being short version (FACIT-Sp12) is a popular measure to assess spiritual well-being in people with chronic illness (Agli et al. 2017; Canada et al. 2008). It provides information about the relationship between spiritual well-being and health-related quality of life. This questionnaire consists of 12 items divided equally in 3 sub-domains of spiritual well-being: meaning, peace, and faith. Items addressed meaning of life, a sense of peace and the relation between illness and one's faith and beliefs. Participants were asked to base their answers to these items on their feelings over the past 7 days. They assessed each item using a 5-point Likert-type scale ranged from 0 "Not at all" to 4 "Enormously." Four scores are provided: 1 for each dimension (ranges from 0 to 12) and an overall score (ranges from 0 to 36). Higher values represent a higher level of spirituality. For the current study, Cronbach's alpha for the total score was high ($\alpha = 0.80$) and for the 3 dimensions meaning, peace, and faith they were 0.73, 0.60, and 0.90 respectively.

## *Data analysis*

Statistical analysis was performed using SPSS 19.0 statistical software. All scale variables were calculated by summing the individual item scores (after relevant reverse scoring). Sociodemographic, social support scores, spirituality scores, and emotional well-being scores were analyzed using descriptive statistics. Before data analysis, the Shapiro–Wilk test was used to check the normality of numeric variables. Pearson correlations were conducted between spirituality, social support, emotional well-being, and participants' characteristics (age, gender, site of ALS, and duration since the announcement of the disease at inclusion). To test the mediational role of spirituality (M) in the link between social support and emotional well-being, 4 simple mediational analyses were performed with Process Model 4, 1 for spirituality (total FACIT-Sp12 score) and 1 for each dimension of spirituality (i.e., meaning, peace, faith). Process Model 4 enables testing of the direct and indirect effects with a single mediator (Hayes 2018). Indirect effects were analyzed by computing bias-corrected 95% confidence intervals (CIs) with 10,000 random bootstraps samples. Statistical significance of the indirect effect was established when zero was not included in the lower and upper level of the CIs.

# Results

## *Participants' characteristics*

Descriptive characteristics of the 36 participants are detailed in Table 1. There were 22 men and 14 women enrolled in the study. Site of onset was spinal in 22 cases and bulbar in the remaining. Mean age at the inclusion was 58.9 years old (SD = 10.6) ranging from 37 to 82 years old. Mean duration between the announcement of the disease and the assessment of the questionnaire was 28.4 months (SD = 17.1). More than half of participants were full-time or part-time workers ($n = 20$), one-third were retired ($n = 12$), and the remaining mostly on disability ($n = 4$). Twenty-two pwALS (61%) were married. Eighteen (50%) lived in a suburban area and the remaining either in a rural area ($n = 9$) or in an urban zone ($n = 9$).

## *Correlations*

All the results of correlations analysis are detailed in Table 2.

There was no correlation between gender, duration since the announcement of the disease, site of onset and emotional well-being, social support, and spirituality.

Good emotional well-being was significantly correlated with a better availability of social support.

There was no significant correlation between emotional well-being and satisfaction with social support.

Total FACIT-Sp12 score was correlated with emotional well-being.
Meaning and peace were correlated with emotional well-being.
Faith was not correlated with emotional well-being.
Total FACIT-Sp12 score was correlated with availability of social support.
Meaning and faith were correlated with availability of social support.
Total FACIT-Sp12 score was not correlated with satisfaction with social support.
Meaning and peace were not correlated with satisfaction with social support.
Faith was positively correlated with availability of social support and satisfaction with social support.

Because of the non-statistically significant results between emotional well-being and satisfaction with social support, no further analyses were performed to test the mediation of spirituality on the relationship between emotional well-being and satisfaction with social support. In the same way, faith was not introduced as a mediator in the analysis.

## *Mediating effects of spirituality on the relationship between social support and emotional well-being*

Spirituality (total FACIT-Sp12 score) significantly mediated the relationship between availability of social support and emotional well-being (indirect effect: $ab = -0.14$, SE = 0.11, 95% CI [−0.38, −0.04]).

Meaning and peace significantly mediated the relationship between availability of social support and emotional well-being

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**Table 1.** Participants' characteristics and mean scores

| | Total sample ($n = 36$) | Men ($n = 22$) | Women ($n = 14$) |
|---|---|---|---|
| Mean age (SD) | 58.9 (10.6) | 60.8 (10.8) | 56 (10) |
| Socioeconomic category | | | |
| Farmers | 0 | 0 | 0 |
| Senior executives | 10 | 6 | 4 |
| Mid-level executives | 2 | 0 | 2 |
| Office workers | 6 | 3 | 3 |
| Workers | 2 | 2 | 0 |
| Retired | 12 | 8 | 4 |
| Others (mostly on disability) | 4 | 3 | 1 |
| Geographic area | | | |
| Urban area | 9 | 4 | 5 |
| Suburban area | 18 | 14 | 4 |
| Rural area | 9 | 4 | 5 |
| Family situation | | | |
| Single | 2 | 1 | 1 |
| Divorced | 5 | 2 | 3 |
| Unmarried couple | 5 | 2 | 3 |
| Married | 22 | 16 | 6 |
| Widowed | 2 | 1 | 1 |
| Site of ALS | | | |
| Bulbar | 14 | 9 | 5 |
| Spinal | 22 | 13 | 9 |
| Duration since the announcement of the disease at inclusion (in months, SD) | 28.4 (17.1) | 29.4 (17.0) | 26.8 (17.8) |
| Availability of home assistance ($n$) | 20 | 12 | 8 |
| Emotional well-being (ALSAQ-EMO) (0–100) – Mean (SD) | 55.63 (4.01) | 61.14 (3.66) | 46.96 (8.26) |
| Social support (SSQ-6) | | | |
| Availability of social support (0–54) – Mean (SD) | 18.08 (2.26) | 17.5 (2.86) | 19 (3.81) |
| Satisfaction with social support (6–36) – Mean (SD) | 28.83 (1.25) | 29.32 (1.59) | 28.07 (2.1) |
| Spiritual well-being (FACIT-Sp12) (0–36) – Mean (SD) | 21.42 (1.45) | 20.18 (1.52) | 23.36 (2.86) |
| Meaning (0–12) – Mean (SD) | 9.47 (0.65) | 9.41 (0.73) | 9.57 (1.26) |
| Peace (0–12) – Mean (SD) | 8.27 (0.55) | 7.64 (0.63) | 8.64 (1.03) |
| Faith (0–12) – Mean (SD) | 3.92 (0.76) | 3.14 (0.74) | 5.14 (1.57) |

SD = standard deviation; ALSAQ = Amyotrophic Lateral Sclerosis Assessment Questionnaire; SSQ-6 = 6-item Social Support Questionnaire; FACIT-Sp12 = 12-item Functional Assessment of Chronic Illness Therapy – Spiritual well-being.

(meaning: indirect effect: $ab = 0.19$, SE = 0.07, 95% CI [−0.35, −0.05]/peace: indirect effect: $ab = 0.18$, SE = 0.09, 95% CI [−0.33, −0.03]).

Participants with higher availability of social support reported higher spirituality ($a = 0.35$, SE = 0.15), which in turn increased emotional well-being ($b = -0.40$, SE = 0.17).

Availability of social support also directly influenced emotional well-being independently of this mechanism (total effect for emotional well-being, $c' = -0.26$, SE = 0.14).

Participants with higher availability of social support reported higher meaning and peace (meaning: $a = 0.40$, SE = 0.16/peace: $a = 0.36$, SE = 0.16), which in turn increased emotional well-being (meaning: $b = -0.47$, SE = 0.15/peace: $b = -0.51$, SE = 0.14).

Availability of social support also directly influenced emotional well-being independently of this mechanism (total effect for emotional well-being, $c' = -0.20$, SE = 0.14).

Models explained around 16% of the variance. The mediational models showing that spirituality and the meaning and peace dimensions mediate the relationship between availability of social support and emotional well-being are summarized in Figure 1. Higher spirituality, meaning, and peace increased the effect of the availability of social support on emotional well-being.

## Discussion

Since the slightest daily activity inexorably worsens until it becomes impossible, pwALS have to renounce each aspect of their life, one after the other. Life as they knew it before the disease is totally upset, leading to a tremendous impact on the psychological sphere. To investigate this issue, we explored the effects of social support on the emotional well-being of pwALS and the mediating role of spirituality in this relationship.

The current study found that social support not only directly affected emotional well-being of pwALS, but also indirectly through spirituality.

First, we highlighted an association between higher perceived social support and better emotional well-being, which confirmed our first hypothesis. The use of a bifactorial questionnaire enabled us to go deeply into our knowledge of the role of social support. Indeed, our results showed that the availability of social support was the only dimension that was correlated with emotional well-being, the satisfaction dimension was not. This result is in line with earlier researches which demonstrate that these 2 dimensions of social support function independently from each other (Harper et al. 2016; Sarason et al. 1983).

The availability refers to the perception of one's potential access to social support. It is the structural social support (Taylor 2011) that is the number and density of social relationships an individual has and the frequency an individual engages with members of his networks. A low level of social bonds has already been proved in several previous epidemiological studies to be a factor of vulnerability, especially among older people (Bruchon-Schweitzer et al. 2003). In our study, the social links also appear to be a key for emotional well-being: participants who perceive higher number of significant others available to them experience higher emotional well-being. Some earlier research has demonstrated similar findings in other patients. For example, Shaheen et al. reported that breast cancer women who perceived higher number of significant others available to them experience less distress than those with perception of low number of significant others available (Shaheen et al. 2015). Similarly, Kazak et al. (1997) in a study of the families of long-term cancer survivors found that the size of social support network of parent(s) of pediatric cancer patients was negatively

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**Table 2.** Correlations (Pearson *r*) between the studied variables

| | 1. EWB | 2. ASS | 3. SSS | 4. SPI | 5. Meaning | 6. Peace | 7. Faith | 8. Age | 9. Gender | 10. DA |
|---|---|---|---|---|---|---|---|---|---|---|
| 2. ASS | −0.40** | | | | | | | | | |
| 3. SSS | 0.03 | 0.39** | | | | | | | | |
| 4. SPI | −0.40** | 0.48** | 0.21 | | | | | | | |
| 5. Meaning | −0.56*** | 0.40** | 0.04 | 0.75*** | | | | | | |
| 6. Peace | −0.59*** | 0.26 | 0.04 | 0.79*** | 0.65*** | | | | | |
| 7. Faith | 0.11 | 0.37* | 0.34* | 0.69*** | 0.11 | 0.27 | | | | |
| 8. Age | 0.42** | −0.12 | 0.05 | −0.05 | −0.21 | −0.22 | 0.22 | | | |
| 9. Gender | −0.29 | 0.05 | −0.08 | 0.15 | 0.01 | 0.09 | 0.21 | −0.21 | | |
| 10. DA | −0.15 | −0.11 | −0.09 | −0.02 | −0.10 | 0.27 | −0.01 | −0.11 | −0.07 | |
| 11. S/ALS | 0.01 | −0.04 | 0.24 | 0.03 | 0.00 | 0.00 | 0.05 | 0.05 | −0.05 | −0.25 |

EWB = emotional well-being; ASS = availability of social support; SSS = satisfaction with social support; SPI = spirituality (total FACIT-Sp12 score); DA = duration since the announcement of the disease at inclusion; S/ALS = site of ALS.
***$p < 0.0001$; **$p < 0.001$; *$p < 0.05$.

associated with symptoms of psychological distress (e.g., anxiety, worry, and traumatic stress).

Thus, more than the satisfaction dimension, the perception of a greater social network (friends, colleagues, family members, relatives, etc.) seems crucial for pwALS. This result is consistent with the study by Zhong et al. (2018) on the association of social support with antepartum depression in which they examined a prospective cohort, and observed a stronger association with a low number of support providers, compared with low satisfaction with social support, on depression risk.

Uchino underlined that not all forms of social support are beneficial and its effectiveness may depends heavily on the context such as the characteristics of the stressor (Uchino 2009). In our study, the effect of high number of support providers may be explained by the specificity of the ALS which loneliness is one of the major psychosocial concern. ALS has substantial impact on social engagement, social identity, and social networks, such as feeling of social isolation and lack of emotional support. This disease leads to continuous severe physical disabilities, pwALS are trapped in an immobile body which drives to more and more feelings of isolation. Preserving relationships with their kin and friends, to still perceive the availability of a social network may be a way of escaping from it, a strong relief that is associated with a good emotional well-being. Concerning the absence of correlation between satisfaction with social support and emotional well-being it may be due to the fact we did not consider the source of support. This point requires further study.

Second, as far as spirituality issues are concerned, our results are in accordance with previous results, showing their bonds with good emotional well-being.

A positive correlation between overall spiritual well-being and emotional well-being was observed. This result is in line with earlier researches dealing with closed issues. Balboni et al. demonstrated that spirituality helps cancer patients cope with their illness and make treatment-related decisions (Balboni et al. 2007). Moreover, in their systematic review of 36 studies, Bai and Lazenby (2015) observed a positive association between overall spiritual well-being and quality of life in the majority of studies. More precisely, except for 2 studies, the association with the emotional dimension was stronger than for the physical one.

The influence of spirituality has been widely studied in patients with adverse health conditions and it has been shown that it can reduce the symptoms of illness by bringing hope, comfort, and value to one's experience (Kamijo and Miyamura 2020; Stoltzfus and Green 2013). In patients with terminal cancer, different authors have acknowledged that it plays a role in consolation, ability to remain peaceful, and happiness in contrast to inevitability, despair, and suicidal ideation (Bovero et al. 2016). Balboni et al. have also demonstrated that spirituality is a positive source that can assist cancer survivors in adjusting their perceptions of unpleasant symptoms and traumatic events, making them more tolerable and improving their quality of life (Balboni et al. 2007). O'Brien and Clark have shown that spirituality helps pwALS make sense of what is happening to them (O'Brien and Clark 2015). Spirituality creates a kind of supportive sense in the individual that improves the meaning-making process (Prati and Pietrantoni 2009), which is a cognitive reappraisal that is particularly important to a successful adaptation under adverse circumstances (Park and Folkman 1997). Under conditions of chronic and severe stress, spirituality and religiosity facilitate positive reappraisals of the difficult situation, and these reappraisals in turn help support positive psychological states (Folkman 1997). Thus, it can be said that spirituality itself acts as a stress-buffering mechanism.

At the scale level, in our study, meaning and peace were positively correlated with good emotional well-being. One explanation would be that having feelings of meaning of life and peace might help pwALS to progress in their acceptance of the disease, which is known to be decisive for their emotional well-being (Hogg et al. 1994). We found no association between faith and emotional well-being. This result is similar to those of previous studies which found a stable association between meaning/peace and emotional well-being whereas faith was not consistently associated with quality of life (Bai and Lazenby 2015; Lazenby et al. 2013; Whitford and Olver 2012). Even if faith is a belief in a higher transcendent power which is not necessarily identified as God (Breitbart 2002), faith often refers to religion. Religion is a personal component that holds different meanings for different countries and ethnicities; thus, different results for the faith score of the FACIT-Sp12 would be expected for different religious groups, nonreligious groups, ethnicities, and countries. We did not take these variables into account

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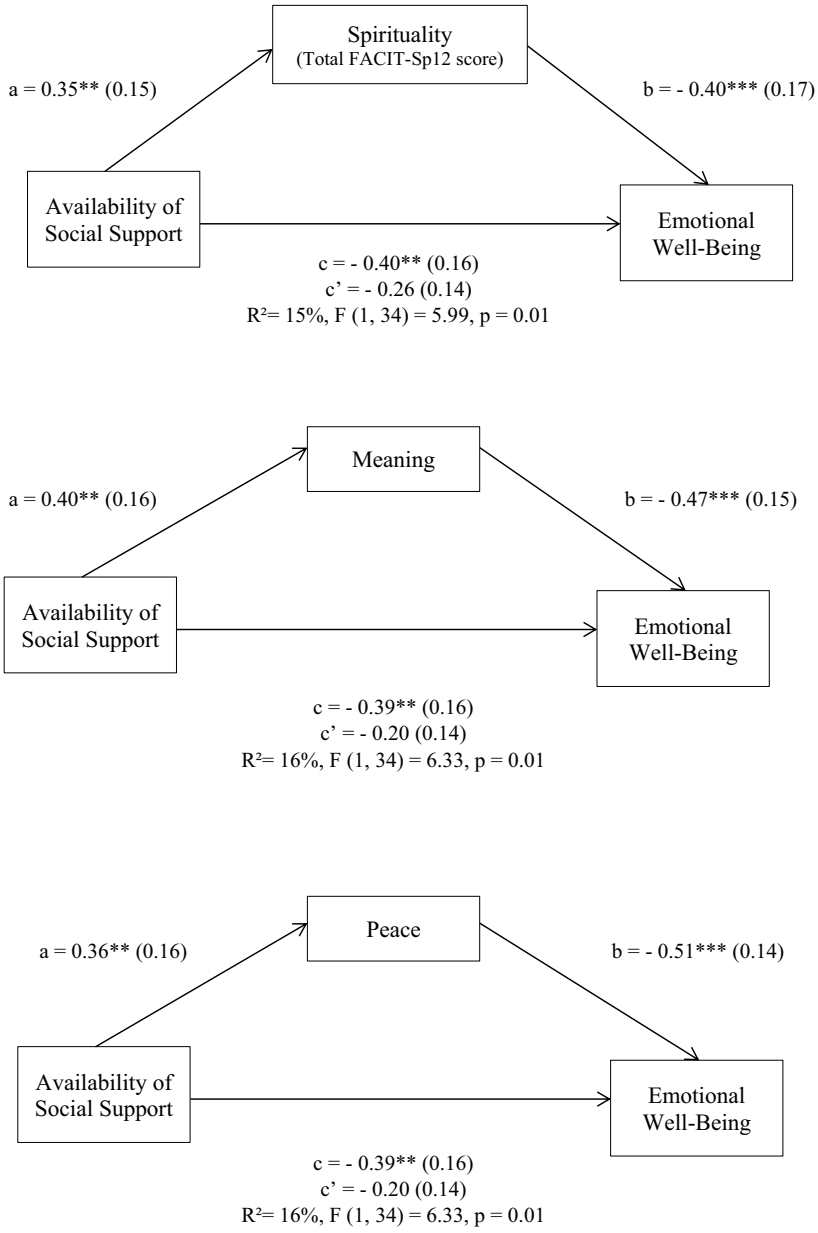


**Figure 1.** Mediating effects of spirituality (total FACIT-Sp12 score), meaning, and peace on the relationship between availability of social support and emotional well-being.

and we can assume that the faith component of spirituality has been associated with religion and religious beliefs, which may explain this specific result concerning the faith factor.

Lastly, our findings suggest that spirituality operates as a mediator between availability of social support and emotional well-being, which confirms our second hypothesis and is a real novel finding which could be explored further. Spirituality provides additional insight into the links between these 2 associated variables.

In our study spirituality appears as a coping strategy for pwALS, which is facilitated by social support.

More precisely, the positive association between good emotional well-being and availability of social support is partly mediated by feelings of meaning of life and peace. A high perceived level of availability of social support by our participants leads to high levels of emotional well-being because it gives them stronger feelings of meaning of life and inner peace. This indirect pathway highlights meaning and peace as a coping strategy that helps pwALS maintain a good emotional well-being.

This result, which is consistent with Folkman's theory of meaning-making as a coping strategy (Folkman 1997), contributes to extend our knowledge of the coping resources used by pwALS. It provides guidance for health-care professionals by interventions that improve this coping skill. In cancer settings, Meaning-Centered Group Psychotherapy developed by Breitbart et al. (2010) showed great success at impacting positively patients' existential well-being, significantly more than standardized supportive psychotherapy intervention. This short-term intervention is designed to help patients with advanced cancer sustain or enhance a sense of meaning, peace, and purpose in their lives, even as they confront death (Breitbart et al. 2010). To include these psychotherapeutic interventions to help pwALS enhance their sense of meaning and inner peace despite their illness seems particularly relevant. Ciria-Suarez et al. (2021) also underlined that other spiritual therapy interventions are valuable to provide life with meaning: relaxation, meditation, mindfulness, may be effective in enhancing spiritual well-being and quality of life to help patients to better cope with their cancer. Finally, this finding also brings to light the necessity to

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include spirituality factors in questionnaires measuring emotional well-being in patients with ALS.

Our results showed that availability of social support preceded and facilitated the use of this coping resource. From a clinical point, this finding suggests another guidance for clinicians' action which is to pay attention to the pwALS' social network and to foster their inclusion in social relationships. Indeed, because of increased physical disabilities pwALS experiment more and more losses in daily life such as loss of job and colleagues, loss of hobbies and partners, loss of almost all that was the core of one's social life. Besides, the disease can frighten and gradually drive friends and relatives away, leading to a psychosocial vulnerability resulting from low social support. In a study dealing with the role of social support among adults with rare diseases, companionship emerges as the strongest type of support positively associated to satisfaction with life (Bryson and Bogart 2020). Companionship support refers to feeling a sense of belonging within a group and engaging in leisure activities with others (Taylor 2011). A way to enable pwALS to meet other individuals with their condition, share time with them, and to feel less isolation may be to foster respite admission in hospitals for patients with intractable neurological diseases.

Although this study provides novel information on underlying mechanisms supporting links between social support, spirituality, and the emotional well-being of pwALS, some limitations should be mentioned. First, these results should be confirmed on a larger sample. Data were collected here via an online survey and this may have led to an underrepresentation of patients who cannot use the internet.

Second, in our study, the mediating effect of spirituality between social support and emotional well-being explained around 16% of the variance, suggesting that other potential mediating variables contribute to this relationship. Novalany (2017) showed in breast cancer patients, that other coping strategies, such as fighting spirit, focusing on the positive, active acceptance, turning to religion improve well-being psychosocial adjustment and quality of life. These variables worth exploring with pwALS. Hence, there are likely a number of factors to take into account. Other internal resources like resilience may also play a decisive part in the buffering process since it has been proved to have a positive relationship with quality of life among patients with breast cancer (Zhang et al. 2017).

Third, in our study, we did not consider the psychological impact of familial history of ALS: having experienced this disease up close in a next of kin can have an impact on pwALS' perceptions and the way they cope with their own disease. In future studies, it would be interesting to examine how this variable affects emotional well-being in pwALS.

Despite these limitations, our exploratory study was one of the first to explore the mediatory role of spirituality in the mechanism by which social support affects emotional well-being and the impacts of the results are of key importance. Alongside the protective effects of social support, we identified that spiritual issues play a major role in the connection between social support and emotional well-being. Spirituality as a coping resource by pwALS is a novel contribution and may lead clinicians to expand their practices including existential and spiritual aspects in their interventions.

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