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Working with suffering: Stress, burnout, and psychological well-being in formal caregivers and volunteers of patients with amyotrophic lateral sclerosis

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Abstract

Background: Amyotrophic lateral sclerosis (ALS) is a rare neurodegenerative disease affecting about 6,000 people in Italy. Caregiving impacts ALS patients' formal caregivers' (FCs) and volunteers' quality of life. Few studies explore this topic.

Objectives: To explore the impact of caregiving on the quality of life of FCs and volunteers.

Methods: Nine FCs (8 women) and seven volunteers (5 women) recruited from a healthcare residence in Italy participated. FCs were 49.29 years old on average (SD = 3.861), with an average service length of 6.58 years (SD = 5.975). Volunteers averaged 62.33 years of age (SD = 5.645) and 7.31 years of service (SD = 5.205). Psychological well-being, perceived stress, burnout, and caregiver abuse were evaluated, alongside online testimonies. Mixed-methods analyses were conducted: nonparametric techniques, Emotional Text Mining, and discourse analysis.

Results: Both FC and volunteers reported moderate perceived stress (M_{FC} = 14.78; SD_{FC} = 6.852; M_V = 12.14; SD_V = 8.235) and high psychological well-being (M_{FC} = 85.86; SD_{FC} = 9.026; M_V = 85.50; SD_V = 14.446). They exhibited low emotional exhaustion (M_{FC} = 16.67; SD_{FC} = 10.087; M_V = 10.14; SD_V = 6.890) and depersonalization (M_{FC} = 2.56; SD_{FC} = 2.186; M_V = 1.33; SD_V = 1.996), with moderate personal gratification (M_{FC} = 29.11; SD_{FC} = 11.667; M_V = 27.43; SD_V = 11.238). About 33.3% (n = 3) of FC and 16.7% (n = 1) of volunteers risk physical or psychological abuse of ALS patients. In online testimonies, research and new therapies for ALS emerged, as well as topics related to patients' and families' needs.

Conclusion: Caregiving affects QoL and carries a risk of burnout. Training and support in equipes may improve caregivers' well-being. Further study of emotional factors could clarify the psychological challenges facing FCs and caregiving volunteers.

Keywords: Formal caregivers; Volunteers; Psychological well-being; Amyotrophic lateral sclerosis; Mixed-method research

1. Introduction

Amyotrophic lateral sclerosis (ALS), also referred to as Motor Neuron Disease (MND), is characterized as a rare, heterogeneous, multisystem progressive neurodegenerative disorder, the etiology of which remains elusive.[1] Worldwide, incidence and prevalence are approximated at 2–4 cases per 100,000 individuals and around six individuals (a figure that is on the rise) per 100,000, respectively.[1-3] In the Italian context, the most recent available data, updated in February 2020 and published by the Italian Association for ALS, obtained from prevalence statistics disseminated by the European Consortium for ALS, indicate that over 6,000 individuals are affected by ALS, with an annual increment of approximately 2,000 cases.

Despite the evident involvement of motor neurons in the typical symptomatology of ALS, ongoing and recent research[4-6] has underscored that this disease also entails the degeneration of additional brain regions that do not govern motor functions, including the limbic system. While the initiating causes of the disease are yet to be fully elucidated, researchers' consensus suggests that at least three risk factors are unequivocally implicated in its etiopathogenesis: genetic mutations and familial history (but also for the 5% of ALS cases), male sex (with a 1.5:1 proportion), and advanced age.[7,8] Conversely, contradictions emerge in investigations concerning potential environmental and social risk factors: there is a notable lack of attention devoted to the possible ramifications of interpersonal interactions.

Nevertheless, limited literature suggests a possible link between shorter telomeres (a DNA sequence) and susceptibility to ALS in adulthood, especially in contexts of elevated stress.[9-11] The clinical syndrome of ALS may originate during neonatal life, influenced by adverse experiences in early life. Previous studies on adverse childhood experiences support this theory, highlighting the vulnerability of motor neurons to neuroinflammation, excitotoxicity, and environmental risk factors.[12] Further research is required to investigate the direct correlation between ALS and adverse childhood experiences.

Given its unique characteristics, the absence of a definitive cure, and the rapid degeneration inherent in the disease, ALS patients must be cared for in healthcare facilities, and this significantly impacts the quality of life (QoL) of both the patient and their caregivers, including formal caregivers (FCs).[13] This is similarly observed in other chronic illnesses,[14] such as Parkinson's disease,[15,16] dementia,[17] fibromyalgia,[18] and cardiovascular diseases.[19] It is widely recognized that individuals enduring chronic disabilities exert a considerable impact, particularly of an organizational nature,[14] on the structuring and organization of their family's life, altering not only its internal dynamics but also the psychological and social well-being of its members. This occurs not only because of the clinical features of the illness, which necessitate caregiver support, but also for relational reasons. For instance, interactions and engagements with the external world often diminish, resulting in heightened importance placed on familial relationships, thus influencing what is categorized as QoL. The World Health Organization (WHO),[20(p1405)] in 1995, defined QoL as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns." Although consensus on a single definition of this concept remains incomplete, most researchers concur with the WHO's definition, which identifies six domains that encompass the critical aspects of QoL: physical well-being, psychological well-being, independence, social relationships, environmental factors, and personal beliefs/spirituality. Chronic diseases, particularly ALS, therefore, significantly affect the psychological and physical well-being of caregivers, especially the formal ones, when patients necessitate placement in a residential or semi-residential nursing facility.[13] Here, medical personnel are tasked with addressing the patient's needs, thereby transitioning them into formal caregiving roles, recognized for their official responsibility within an institutional framework and compensated accordingly.[21] Chronic illness, therefore, impacts the well-being and QoL of caregivers frequently interacting with patients and providing them with formalized and sustained care.[22] Numerous studies have illustrated that burnout, defined by the WHO in the International Classification of Diseases, 11th Revision, as a syndrome stemming from chronic, unmanageable workplace stress that adversely affects health and QoL, is prevalent among professionals in caregiving roles and those engaged in social and healthcare settings, and especially in women.[23-26] Contradictions arise, however, regarding the correlation with years of experience as a FC. Some research posits that younger caregivers are at greater risk for work-related stress and burnout due to a lack of coping strategies and reduced experience in managing high-stress situations;[27] conversely, other studies suggest that more experienced caregivers face a high risk due to greater accumulation of experiences, including those that may be stressful.[28] Ultimately, having children or a family unit appears to serve as a protective factor.[29] In the specific context of ALS, for which palliative care is particularly critical during the terminal phase, deficits still persist in examining the psychological well-being of caregivers; consequently, a thorough exploration of this issue is deemed essential for developing strategies and resources

aimed at alleviating the impact on QoL and fostering the psychological well-being of caregivers and volunteers. In the literature, it is also important to understand what themes emerge from the narratives of caregivers when talking about their work with ALS patients and families.[30] In fact, in the few studies that have been conducted, it emerges that FCs' testimonies mainly highlight priorities for patients and families.[21] No studies were conducted involving ALS volunteer caregivers. Consequently, there is a lack of exploration into FCs' and volunteers' experiences, emotions, and feelings related to caring for ALS patients.

In light of the lack of information about the aforementioned issues within the literature, combined with insights drawn from various studies referenced previously, we conducted this research adopting an interdisciplinary and comprehensive lens focused on these aspects, necessary to broaden the understanding of the QoL of formal and volunteer caregivers, particularly through the promotion of well-being and the enhancement of psychological (and other) resources, a key tenet of health psychology.

The main objective of this study is to investigate the impact of ALS, at a preliminary level and from an interdisciplinary perspective, to contribute to a deeper understanding of the potential psychosocial factors that may influence FCs' and volunteers' lives in caregiving and personal life settings. We hypothesized that caregivers and volunteers report a low level of well-being and high levels of stress and burnout. Given the preliminary nature of the study, we also exploratively investigated potential associations between perceived stress, psychological well-being, burnout, and risk of abusive or neglectful behaviors. These correlational analyses were intended as hypothesis-generating rather than confirmatory. We also aimed to analyze the meaning of ALS for FCs and volunteers, to identify collective representations and symbolic categories, and to provide targeted support, as well as to examine the themes and dimensions of ALS. We aimed to emphasize the importance of deepening knowledge of ALS beyond medical understanding to include psychological, emotional, and social dimensions.

2. Methods

The research comprised two complementary exploratory studies, conducted using different methodological approaches and involving distinct populations. Numerical data from the first study provide a preliminary and exploratory assessment of the psychological dimensions investigated, while the second study combines quantitative textual analysis with qualitative interpretation to examine subjective experiences and contexts in depth. The complementary consideration of the two studies provides different perspectives on the experience of caring for people with ALS, without assuming that findings from one study confirm those of the other.

After conducting a careful literature review, we structured the research project into two studies. The first study involved FCs and volunteers from a nursing home. After observing the facility, getting to know the participants, and learning more about the disease, we recruited participants for the first study. This study was reported in accordance with the STROBE guidelines. The research was approved by the Lombardy 2 Regional Ethics Committee at its meeting on December 11, 2024 (protocol code: L2-270). The research was also conducted in accordance with the ethical principles outlined in the Declaration of Helsinki. Each participant included in the study provided their informed consent to participate in the research and to be published. The second study, however, involved collecting online testimonials. This study was reported in accordance with the Standards for Reporting Qualitative Research guidelines. This part of the research did not involve participant recruitment or sensitive data. Following a preliminary review by the University of Bergamo Committee for Integrity and Research Ethics, the project was deemed non-applicant for ethical evaluation. Nevertheless, the study adhered to the principles of the Declaration of Helsinki, and all online testimonies were anonymized.

Since conducting qualitative interviews with the caregivers from the quantitative phase was not feasible—given the study timeline, the small sample size, and the anonymous recruitment method, which did not allow for subsequent recontact with participants—an analysis of publicly available online testimonials was conducted. These testimonials were not considered to belong to the same population as the quantitative sample, nor were they used to confirm or validate the quantitative results. Instead, they served as a complementary qualitative source to explore the quantitative findings in greater depth from an experiential perspective. The two studies were conducted and analyzed independently, and their findings were considered together only at the interpretive stage, by examining potential points of convergence and divergence. This comparison was intended to generate interpretive insights and hypotheses for future research rather than to establish direct correspondence between the two datasets.

2.1. Study 1: Villa dei Cedri's formal caregivers and volunteers

The first part of this study was conducted in collaboration with Villa dei Cedri nursing home in Merate (Lecco), an institution accredited by the Lombardy Region since

2003, that provides up to 120 beds for non-self-sufficient elderly individuals, including those with Alzheimer's disease or dementia, as well as individuals with ALS and/or neurodegenerative conditions. As noted on their website, Villa Dei Cedri is a villa surrounded by a large park exceeding 130,000 m^2, organized like a hotel complex, with medical and healthcare personnel working around the clock. Among the various services provided, a Church Chapel serves as a space for devotion, reflection, and prayer. Specifically, in the ALS unit, 14 beds are dedicated to patients and equipped with centralized oxygen therapy and broncho-aspiration facilities at the patient's bedside. The professionals and volunteers employed in this establishment are meticulously selected and trained for the care of individuals with such diseases. Lastly, patient care is based on a collaborative effort and an individualized care relationship, with family members actively involved in formulating personalized care plans. It is crucial to define and clarify the research context, as it aids in interpreting the results derived from the data analysis. The research was approved by the Lombardy Territorial Ethics Committee 2.

Thanks to Villa dei Cedri's collaboration, we recruited 16 participants: nine healthcare workers (hereinafter referred to as FC) and seven volunteers. All participants were recruited voluntarily and work in the ALS unit. Among FCs, only one was male; the age range was 44 to 53 years (M = 49.29; standard deviation [SD] = 3.861), and the average length of service was 6.58 years (SD = 5.975). Different professionals were involved, including an auxiliary social worker, social worker, nurse, physician, physiotherapist, professional educator, and occupational health worker. Regarding volunteers, there were only two males; the age range was 51 to 66 years (M = 62.33; SD = 5.645), and the average length of service was 7.31 years (SD = 5.205). Table 1 shows the sociodemographic characteristics of FCs and volunteers. To be included in the study, FCs and volunteers had to work in a unit or team that deals with people diagnosed with ALS and understand Italian. We did not include any exclusion criteria.

Before starting the questionnaire battery, each participant had to provide informed consent to participate and to the use of aggregated data for research and publication purposes. Only upon acceptance of informed consent, privacy, and data processing information were participants able to complete the battery of questionnaires in an online form using Google Forms.

For each included questionnaire, we have reported the reliability indices for the scales based on their Italian validation, since these indices could not be calculated for our sample due to its small size. The first questionnaire included in the battery was the Perceived Stress Scale (PSS10):[31,32] a 10-item self-report questionnaire with a 5-point Likert scale (0 = never to 4 = very often) to explore perceived stress feelings and thoughts experienced during the past month. The questionnaire includes a total score (max = 40; Cronbach's alpha = 0.74), derived from the sum of responses to all items, and two subscale scores. The first one is related to perceived helplessness (items 1, 2, 3, 6, 9, and 10; max = 24; Cronbach's alpha = 0.84), namely personal feelings related to lack of control over circumstances, emotions, and interpersonal relationships. The second is related to self-efficacy (items 4, 5, 7, and 8, all reverse-coded; max = 16; Cronbach's alpha = 0.72), namely perceived inability to handle the problems one faces. A high score, either total or on either subscale, indicates a greater presence of personal stress.

Table 1. Sociodemographic characteristics of participants

Characteristics	Formal caregiver (n = 9)		Volunteers (n = 7)	
	N	**%**	***N***	**%**
Gender				
Male	1	11.1	2	28.6
Female	8	88.9	5	71.4
Relationship status				
Married	4	44.4	6	85.7
Divorced/separated	4	44.4	1	14.3
Single	1	11.1	0	0.0
Educational level				
≤8 years	0	0.0	3	42.9
>8 years	9	100.0	4	57.1

The second questionnaire was the Psychological Well-Being Scale (PWB18):[33,34] a 18-item self-report questionnaire with a 6-point Likert scale (1 = it is not my case to 6 = it is just my case) that explores six dimensions of psychological well-being (max score for each one is 18): autonomy (items 9 reverse, 11, and 18), environmental control (items 1, 3 reverse, and 6), personal growth (items 7, 15, and 17 reverse), positive interpersonal relationships (items 4 reverse, 12, and 13 reverse), purpose in life (items 5 reverse, 14, and 16 reverse), and self-acceptance (items 2, 8, and 10 reverse). It can also be calculated as a total score (max = 108; Cronbach's alpha = 0.85[1]), derived from the

[1] Only the internal consistency coefficient for the total scale validated in Italian is reported here, since the literature does not provide specific Cronbach's alpha values for the various subscales.

sum of responses to the scales, and a higher score indicates a higher level of psychological well-being.

The third questionnaire was the Maslach Burnout Inventory (MBI):[25,35] a 22-item self-report questionnaire with a 7-point Likert scale (0 = never to 6 = every day) that explores the burnout syndrome in its three independent dimensions. The first dimension is emotional exhaustion (items 1, 2, 3, 6, 8, 13, 14, 16, and 20; max = 54; Cronbach's alpha = 0.87), i.e., a negative experience of emotional coldness and disinterest in one's work and others. The second dimension is depersonalization (items 5, 10, 11, 15, and 22; max = 30; Cronbach's alpha = 0.68), i.e., a negative experience of enacting cold and impersonal responses and behaviors toward users. The third dimension is personal gratification and fulfillment (items 4, 7, 9, 12, 17, 18, 19, and 21; max = 48; Cronbach's alpha = 0.76), i.e., a positive perception of one's competence and desire for success in working with others. A total high score in the first two sections and a low score in the last section may indicate burnout. Each dimension can also be divided into three categories, depending on relative risk. There is a high risk of emotional exhaustion burnout when the total score is greater than or equal to 30; the risk is moderate if the score is between 18 and 29, and it is low if the score is less than or equal to 17. There is a high risk of depersonalization burnout when the total score is greater than or equal to 12; it is moderate if the score is between 6 and 11, and it is low if the score is less than or equal to 5. Finally, the burnout risk scores on the scale of personal gratification and accomplishment should be interpreted in reverse, as a higher score on this scale indicates a higher level of well-being, and thus a lower risk of burnout: there is a high risk if the score is less than or equal to 33, moderate if the total score is between 34 and 39, and low if the score is greater than or equal to 40.[25,35]

The last questionnaire was the Caregiver Abuse Screen (CASE):[36,37] an 8-item self-report questionnaire (Cronbach's alpha= 0.86)[2] with a dichotomous response scale (Yes/No) related to the last year of employment, to examine the possible risk of physical and/or psychological abuse and neglect that might occur in residential and semi-residential facilities by the FC toward the patient, because of perceived stress. If the total score is greater than or equal to 4, people may have a high risk of enacting a form of abuse toward the elderly and/or fragile people. Two components of abuse can also be calculated, at the descriptive level, which relate to neglect (items 5 and 7) and physical and psychological interpersonal abuse (items 1, 2, 3, 4, 6, and 8). Again, the higher the score obtained, the greater is the likelihood of enacting these behaviors.

Score classifications were based on the normative and interpretative criteria provided by the Italian validation studies of each instrument. For all questionnaires used that require copyright permission, the authors declare that they have obtained a license to use them.

At the end of all the questionnaires, a series of sociodemographic questions was included to gain information about FCs' and volunteers' age, gender, education level, marital status, time of service at the nursing home, role in the team, and department of service.

Given the small sample size, non-parametric statistical analyses were performed. Descriptive statistics were first calculated separately for FCs and volunteers. Differences between the two groups in the psychological variables were explored using the Mann–Whitney *U* test for independent samples. Effect sizes were also calculated for these comparisons.

Spearman's rank-order correlations and multiple-comparison adjustments were subsequently performed, separately for FCs and volunteers to explore potential associations among the psychological dimensions considered. Given the small sample sizes, these correlation analyses were considered exploratory and hypothesis-generating rather than confirmatory, and their results were interpreted accordingly.

Missing data in the correlation analyses were handled using pairwise deletion. Thus, each Spearman correlation was calculated using all participants with valid data for both variables included in the respective analysis. Consequently, the effective sample size could vary across correlations because of missing observations.

Correlation analyses focused on associations between dimensions belonging to different psychological constructs (PSS10, PWB18, MBI, and CASE), in accordance with the exploratory aims of the study. Correlations between dimensions belonging to the same construct were not included. The effective sample size (n) was determined separately for each correlation on the basis of the available paired observations; therefore, it could vary across analyses because of missing data and is reported for each correlation. To account for the increased risk of Type I error arising from multiple testing, p-values were adjusted using the Benjamini–Hochberg false discovery rate (FDR) procedure. Multiple-testing adjustment was performed separately for FCs and volunteers and within each family of comparisons defined by pairs of psychological constructs (PSS10–PWB18, PSS10–MBI, PSS10–CASE, PWB18–

[2] Only the internal consistency coefficient for the total scale validated in Italian is reported here, since the literature does not provide specific Cronbach's alpha values for the two descriptives subscales.

MBI, PWB18–CASE, and MBI–CASE). Both unadjusted and adjusted *p*-values are reported to ensure transparency.

Given the exploratory nature of the correlation analyses and the small sample sizes, emphasis was placed on the magnitude and direction of Spearman's rho, the effective sample size, and multiplicity-adjusted *p*-values, and no causal interpretation was attributed to the observed associations.

Descriptive and group-comparison analyses were performed using the Statistical Package for Social Sciences (SPSS version 29.0.1.0, IBM, United States). Correlation analyses and multiple-comparison adjustments were performed in R (version 2.7.5, R Foundation for Statistical Computing, Austria) using the Rj Editor module implemented in jamovi.

2.2. Study 2: Online testimonies data collection and mixed-methods analysis

For the second exploratory study, 118 spontaneous narratives written in Italian were collected from 38 publicly accessible websites, including ALS and health-related association websites, forums and personal blogs, magazines, and online newspapers. The online search and data collection were conducted between February and April 2025. All narratives originated from Italian online sources and were written in Italian. Where available, the publication date was recorded; however, publication dates were not consistently available for all narratives. Narratives were identified on websites with dedicated sections where patients, family members, volunteers, FCs, or other individuals involved in ALS could spontaneously share their experiences. Only publicly available narratives that had been produced spontaneously, rather than elicited through interviews or researcher-generated questions, were included. Eligibility also required that the narrator's relationship with ALS could be clearly established from the information provided in the original source. Each narrator contributed only one testimony to the corpus; no individual was represented by more than one narrative. For the subgroup relevant to the present study, classification as an FC or volunteer was based on an explicit self-description of the narrator's professional or voluntary role within the testimony itself. Narratives for which the author's role could not be determined with sufficient certainty were excluded. Thus, classification was based on explicit textual evidence rather than assumptions derived from the narrative content. The narratives were analyzed in their original Italian language and were anonymized by removing names and references that could identify individuals or places.

The resulting corpus comprised 118 narratives: 67 produced by people with ALS, 41 by inFCs, and 10 by FCs and volunteers involved in ALS care or related activities. Analyses were carried out on all narratives using a mixed-methods approach; however, in this study, only findings specifically concerning the 10 narratives produced by FCs and volunteers are reported and interpreted, in line with the aims of the present research. The 10 narratives varied substantially in length, ranging from 42 to 764 words, with a mean length of 366.7 (SD = 284.46) words. The other groups were therefore used to construct and analyze the overall textual corpus, but their specific findings are presented in our other articles.

The quali–quantitative textual analysis was conducted first through the Emotional Text Mining technique[38,39] with T-LAB Plus 2022 (version 7.2.1.4, T-LAB, Italy)[40-42] and then through discourse analysis[43] and positioning analysis.[44] In this way, it was possible to obtain an initial general overview, with quantitative grounding, related to the implicit axes of communication and emerging themes[39] and, secondly, to qualitatively deepen the analyses to better understand the meaning of themes and dimensions related to ALS, integrated within the social context in which they are produced.[45]

All narratives were coded using a progressive identification number and categorical variables identifying the narrator's group and gender and were subsequently merged into a single textual corpus comprising 81,752 tokens. Preliminary lexicometric analyses included the number of tokens, type/token ratio, and hapax percentage, which were used to assess the lexical characteristics and adequacy of the corpus. The texts were then segmented into elementary contexts, and a customized dictionary was constructed after removing stop words, stimulus-related terms, and words outside the established frequency thresholds. The lower frequency threshold was set at 10, corresponding to the size of the smallest group (here presented), and the upper threshold at 226, corresponding to a specific formula result, resulting in a final dictionary of 746 keywords. Thematic classification of the elementary contexts was performed using a bisecting k-means algorithm, followed by correspondence analysis. The procedure classified 96.63% of the elementary contexts and identified five thematic clusters positioned within four factorial communication axes. Associations between clusters and group/gender variables were examined using chi-square tests and standardized residuals. Semantic interpretation of the factorial axes and thematic clusters was independently performed by three trained judges; their classifications were subsequently compared, and disagreements or ambiguous cases were discussed until unanimous consensus was reached. Finally, the quantitative

textual results were complemented by qualitative discourse analysis and positioning analysis. The narratives and text excerpts identified through Emotional Text Mining were examined in their original linguistic and socio-cultural context to deepen interpretation of explicit themes, implicit communication axes, and how narrators constructed their own and others' roles in relation to ALS. In this case, the three independent judges adopted a reflexive approach by comparing alternative interpretations and repeatedly returning to the original narratives and their socio-cultural context before assigning final meanings to themes and dimensions. Interpretations were therefore treated as analytically constructed readings of the texts rather than as objective properties inherent in the narratives.

3. Results

3.1. Study 1: Villa dei Cedri's formal caregivers and volunteers

The Mann–Whitney *U* tests revealed no statistically significant differences in the psychological variables between FCs and volunteers, but this finding may reflect the limited sample size. In fact, rank-biserial correlations (*r*rb), calculated as effect-size measures for the Mann–Whitney *U* tests, indicated small to moderate effects across comparisons.[3]

Concerning perceived stress, both FCs and volunteers exhibit moderate stress levels overall and in two sub-dimensions, as shown in Figure 1. The results presented in the following sections are exploratory and preliminary. Furthermore, since they pertain specifically to the staff at Villa dei Cedri, they cannot be generalized to other social and healthcare contexts.

Specifically, the average total score stands at 14.78 (SD = 6.852) for FCs and 12.14 (SD = 8.235) for volunteers, on a total scale of 40, where higher total scores reflect more personal stress. Thus, indicating an average presence of stress. Participants also scored moderately in perceived helplessness (M_{ci} = 8.11; SD_{ci} = 5.510; M_V = 6.57; SD_V = 5.062) and lack of self-efficacy (M_{FC} = 6.67; SD_{FC} = 2.915; M_V = 5.57; SD_V = 3.910). These results suggest that both FCs and volunteers fall within the middle range regarding feelings of lack of control over their circumstances, emotions, and relationships, and perceive an inability to manage challenges without extreme scores.[46]

Consistent with these results, both FCs and volunteers exhibit high levels of psychological well-being across the total and six subscales, as shown in Figure 2, because higher scores reflect greater psychological well-being. Note that the maximum obtainable score is 108 for the total scale and 18 for each dimension.[34]

Referring to the total score, both FCs (M = 85.86; SD = 9.026) and volunteers (M = 85.50; SD = 14.446) showed high overall psychological well-being. This is further supported by high scores across the six scale dimensions. A high score on the autonomy scale indicates that FCs (M = 16.00; SD = 1.852) and volunteers (M = 15.43; SD = 2.936) are self-confident, independent individuals who resist social pressures. They can also assess themselves based on their personal standards (ibidem). Regarding environmental control, where scores are similarly high, results indicate that FCs (M = 13.50; SD = 2.828) and volunteers (M = 13.00; SD = 3.899) feel they can manage their surroundings effectively, leveraging opportunities that arise to meet their needs (ibidem). High scores are also noted in personal growth (M_{FC} = 15.63; SD_{FC} = 1.996; M_V = 15.00; SD_V = 2.646), indicating a continual sense of growth among participants. They are open to new experiences and strive to reach their potential, suggesting an inclination towards change that fosters greater self-awareness (ibidem). The score for positive interpersonal relationships is also strong, indicating that FCs (M = 12.85; SD = 3.805) and volunteers (M = 15.29; SD = 2.430) cultivate trusting interactions characterized by empathy and intimacy (ibidem). Participants also report a high purpose of life score (M_{FC} = 13.63; SD_{FC} = 2.264; M_V = 14.50; SD_V = 2.881), signifying clarity around life goals and the capacity to attach meaningful significance to past and present experiences (ibidem). Lastly, self-acceptance scores are high (M_{FC} = 13.63; SD_{FC} = 1.996; M_V = 12.43; SD_V = 4.198), reflecting positive self-regard and awareness of their strengths and weaknesses (ibidem). All findings display consistency.

Results on mean scores in the three dimensions of the Maslach Burnout Inventory, emotional exhaustion, depersonalization, and personal gratification and

[3] The effect sizes for the nonparametric Mann–Whitney *U* test used to compare the independent groups were found to be zero or moderate: for the PSS10 dimensions, *r*rb = −0.190 for the total score, −0.111 for perceived helplessness, and −0.143 for lack of self-efficacy; for the PWB18 dimensions, *r*rb = 0.048 for the total score, −0.143 for self-acceptance, 0.063 for purpose in life, 0.449 for positive interpersonal relationships, −0.232 for personal growth, −0.063 for environmental mastery, and 0.000 for autonomy; for the MBI dimensions, *r*rb = −0.429 for emotional exhaustion, −0.389 for depersonalization, and −0.111 for personal accomplishment; for the CASE dimensions, *r*rb = −0.315 for the total score, 0.000 for neglect, and −0.444 for interpersonal physical/psychological abuse. Overall, the effect sizes ranged from negligible to moderate; however, given the small sample size, these estimates should be interpreted cautiously.

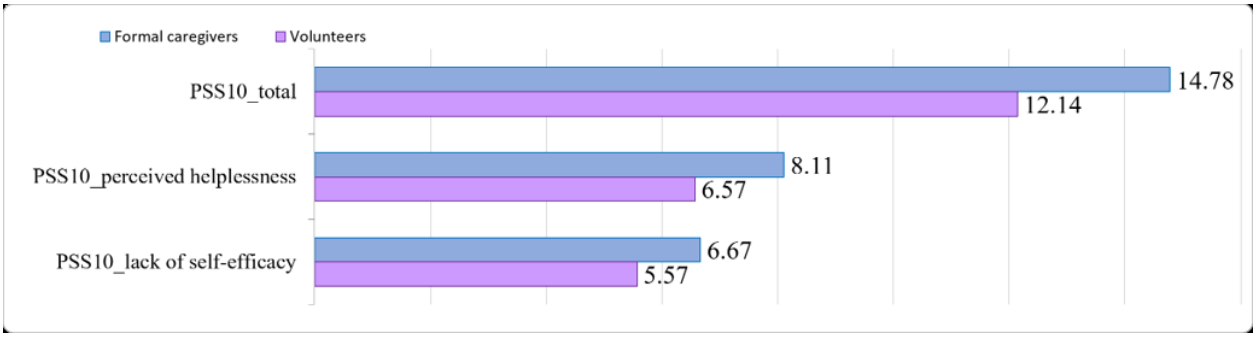


Figure 1. Formal caregivers' (n = 9) and volunteers' (n = 7) mean scores of the Perceived Stress Scale (PSS10) and its dimensions

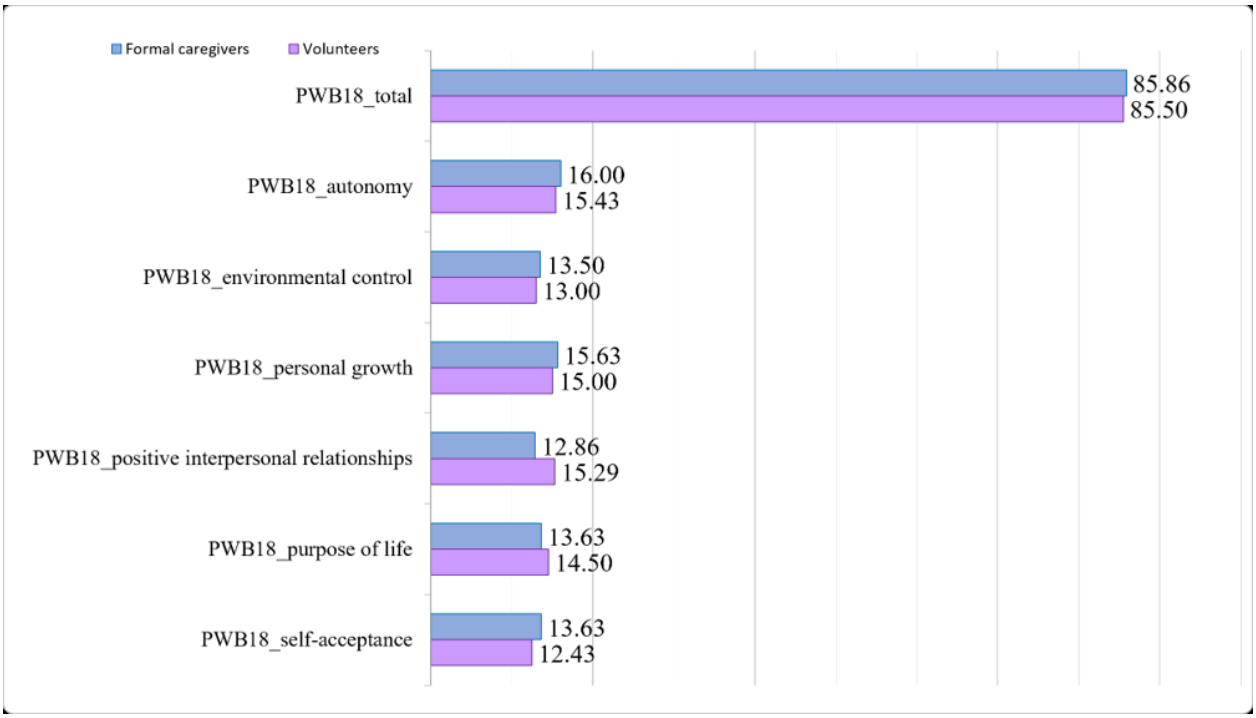


Figure 2. Formal caregivers' (n = 9) and volunteers' (n = 7) mean scores of the Psychological Well-Being Scale (PWB18) and its dimensions

fulfillment, are shown in Figure 3.

Both FCs and volunteers demonstrate low emotional exhaustion (M_{FC} = 16.67; SD_{FC} = 10.087; M_V = 10.14; SD_V = 6.890) and depersonalization (M_{FC} = 2.56; SD_{FC} = 2.186; M_V = 1.33; SD_V = 1.966), along with moderate levels of personal fulfillment (M_{FC} = 29.11; SD_{FC} = 11.667; M_V = 27.43; SD_V = 11.238). These results indicate that FCs and volunteers in the ALS department experience low levels of emotional detachment and disinterest in their work and others, alongside a moderate to high perception of their competence and desire for success in collaboration with others, suggesting a lower risk of burnout.[35] To assess this burnout risk better, the levels of risk within each dimension were classified as low, medium, or high (ibidem), and the results are displayed in Figure 4.

Most FCs and volunteers have a low risk of burnout related to emotional exhaustion (66.7%; n = 6 for FCs; 71.4%; n = 5 for volunteers) and depersonalization (88.9%; n = 8 for FCs; 85.7%; n = 6 for volunteers). They also show a low likelihood of experiencing burnout due to low personal gratification (55.6%; n = 5 for FCs; 57.1%; n = 4 for volunteers). These results could be due to the work and environmental context (Villa del Cedri) within which they are surrounded. Regarding the mean scores of the last questionnaire we were interested in, the Caregiver Abuse Screen, the results are shown in Figure 5.

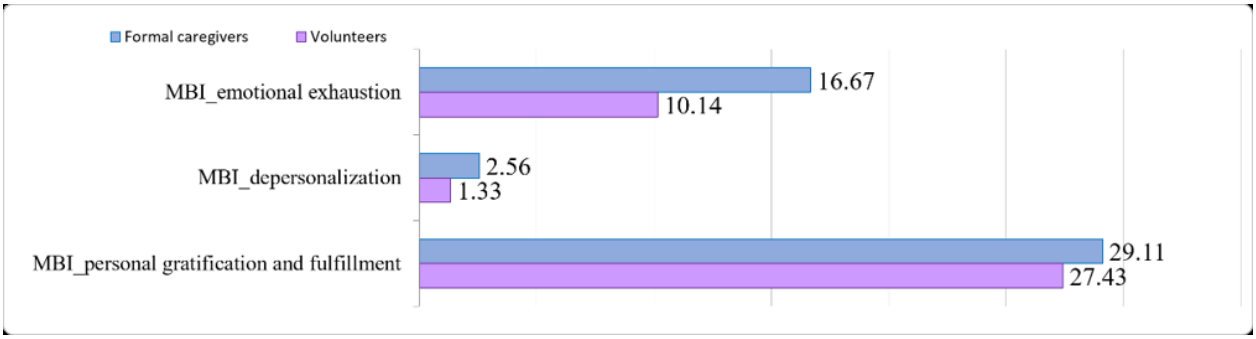


Figure 3. Formal caregivers' (n = 9) and volunteers' (n = 7) mean scores of the three dimensions of the Maslach Burnout Inventory (MBI)

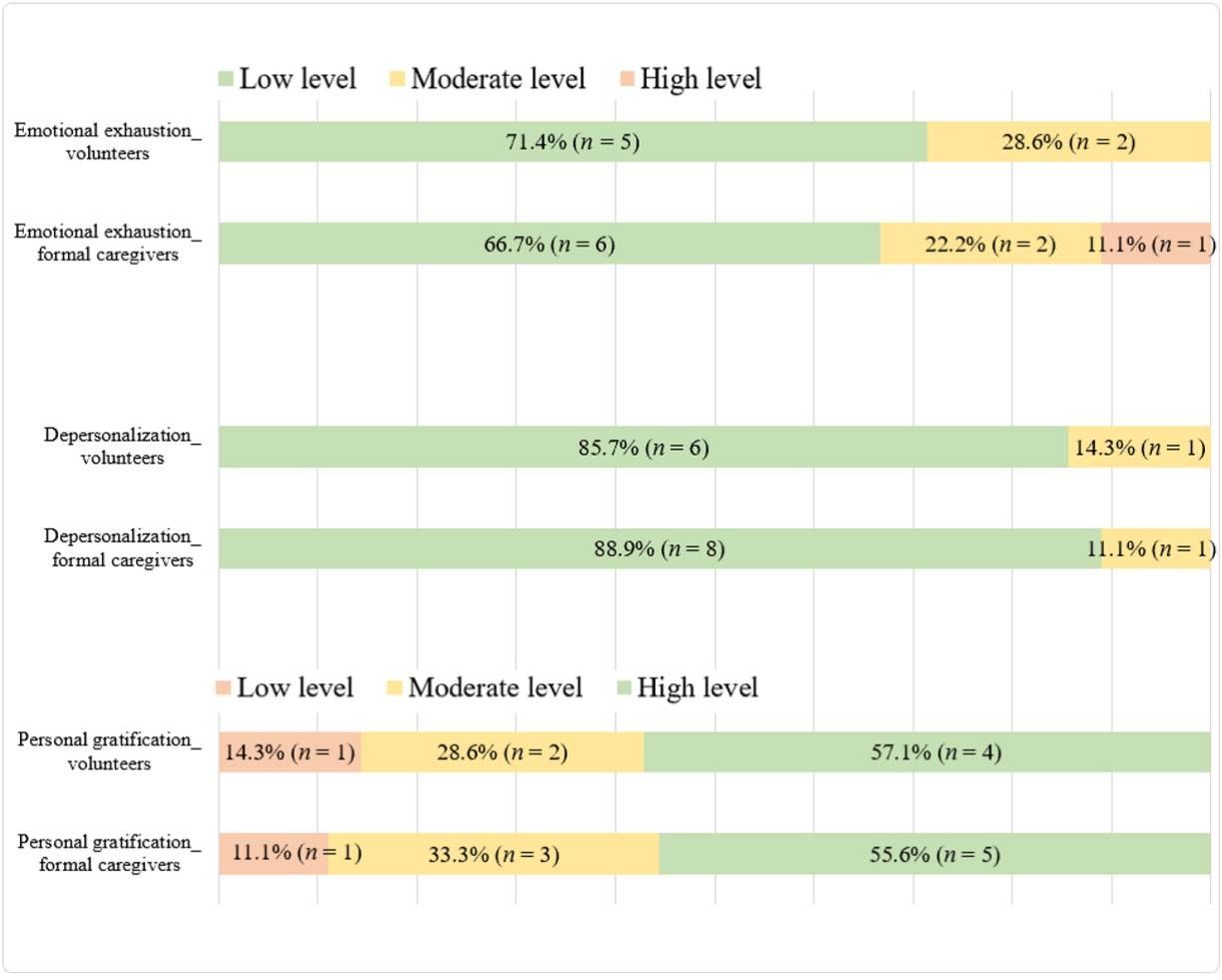


Figure 4. Formal caregivers' (n = 9) and volunteers' (n = 7) risk of burnout in the three dimensions of the Maslach Burnout Inventory

Generally, a score of 4 or higher indicates a greater risk of physical or psychological abuse and/or neglect of patients.[36] Our participants, specifically FCs, attain an average score of 3.56 (SD = 2.744), which is close to the threshold of 4. The scores in both subscales are similarly near the threshold, given that the maximum score is 2 for neglect and 6 for interpersonal physical/psychological abuse. Given these scores, special attention should be paid

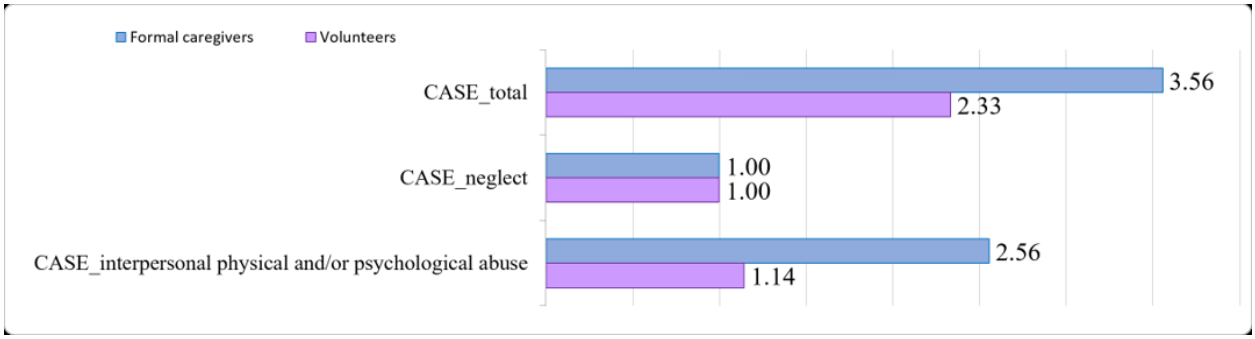


Figure 5. Formal caregivers' (n = 9) and volunteers' (n = 7) mean scores of the Caregiver Abuse Screen (CASE) and its dimensions

to this result. Figure 6 details the percentage distribution of those at risk of engaging in abusive behaviors towards ALS patients.

Notably, 33.3% (n = 3) of FCs and 16.7% (n = 1) of volunteers screened positively at the specified CASE cut-off. Fortunately, the largest percentage in both groups do not appear to be at risk of such abusive conduct. It is also important to emphasize that no abuse events were documented, investigated, or independently verified in this study.

After exploring participants' psychological well-being across the facets described above, we conducted exploratory Spearman correlation analyses, separately for FCs and volunteers, to investigate potential associations among the different psychological dimensions. Given the small sample sizes, these analyses were considered hypothesis-generating rather than confirmatory. To account for multiple comparisons, p-values were adjusted using the Benjamini–Hochberg FDR procedure within each predefined family of comparisons. All the correlations are reported in Tables 2 and 3.

For FCs, three correlations remained statistically significant after FDR correction. Higher perceived helplessness was strongly associated with lower environmental mastery ($rho(8) = -0.890$, $p = 0.003$, pFDR = 0.037). Higher perceived helplessness was also associated with higher overall CASE scores ($rho(9) = 0.790$, p = 0.011, pFDR = 0.036) and higher interpersonal physical/psychological abuse scores ($rho(9) = 0.786$, $p = 0.012$, pFDR = 0.036). Other associations that reached significance at the unadjusted level did not remain statistically significant after FDR correction (Table 2). Given the small sample size, these associations should be interpreted cautiously and considered exploratory. For volunteers, several strong correlations were observed at the unadjusted level; however, none remained statistically significant after FDR correction. Nevertheless, two associations showed a trend toward statistical significance after correction: higher perceived helplessness was associated with higher emotional exhaustion ($rho(7) = 0.857$, $p = 0.014$, pFDR = 0.082), while higher positive interpersonal relationships were associated with lower emotional exhaustion ($rho(7) = -0.906$, $p = 0.005$, pFDR = 0.088). Other associations observed at the unadjusted level did not remain statistically significant after FDR correction (Table 3). Given the small sample size and the exploratory nature of the analyses, these trends should be interpreted cautiously and require confirmation in larger samples. We also analyzed any possible gender and education differences, both for FCs and volunteers, but no statistically significant differences were found in either group concerning the psychological variables examined. Regarding nationality, the limited number of foreign participants precluded further analysis.

3.2. Study 2: Online testimonies

For the aim of the present article, the results concern exclusively the material attributable to the 10 FCs and volunteers, while the complete analyses of the three groups are reported in our other studies.[47,48]

The five themes, related to ALS, that emerge from our previous analysis are disease onset, difficulties, medical examinations, coping, and needs. Each of these themes can be collocated into the four dimensions of ALS communications, which are: disease management, assistance, support, and effort. The themes and the dimensions are related to the socio-cultural context in which reality is constructed. The themes are explicit narrative parts; the dimensions are implicit parts of communication and may be generalized to the ALS discourses. Each dimension is in a two-opposite-poles continuum, with respective disequilibrium effects.[38,39]

In general, narratives produced by FCs and volunteers appear to be less likely than those of family members and patients to discuss their needs and the difficulties they encounter during their work or volunteer service. A

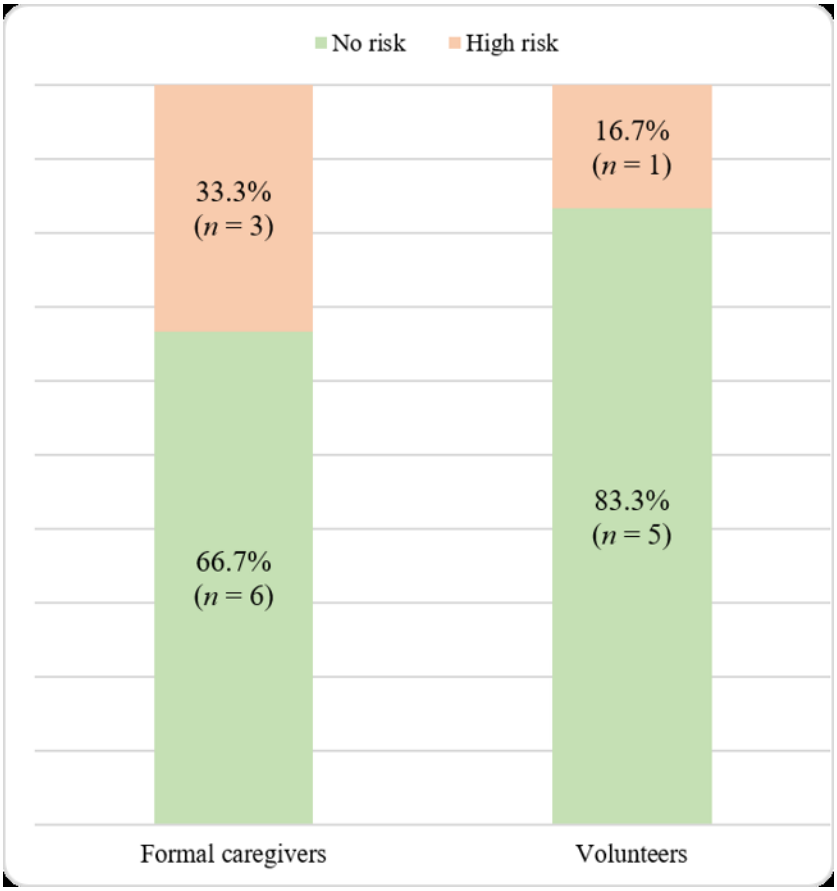


Figure 6. Formal caregivers' (n = 9) and volunteers' (n = 7) risk of caregiving abuse

Table 2. Exploratory Spearman's rank-order correlations among psychological dimensions in formal caregivers

Construct pair	Variable 1	Variable 2	*n*	Spearman's *rho*	*p*	*p*FDR
PSS10–PWB18	Lack of self-efficacy	Autonomy	8	0.537	0.170	0.407
PSS10–PWB18	Lack of self-efficacy	Environmental mastery	8	−0.539	0.168	0.407
PSS10–PWB18	Lack of self-efficacy	Personal growth	8	−0.499	0.209	0.417
PSS10–PWB18	Lack of self-efficacy	Positive interpersonal relationships	7	−0.109	0.816	0.816
PSS10–PWB18	Lack of self-efficacy	Purpose in life	8	0.130	0.760	0.816
PSS10–PWB18	Lack of self-efficacy	Self-acceptance	8	−0.733	0.038	0.231
PSS10–PWB18	Perceived helplessness	Autonomy	8	0.391	0.338	0.579
PSS10–PWB18	Perceived helplessness	Environmental mastery	8	−0.890	0.003	0.036*
PSS10–PWB18	Perceived helplessness	Personal growth	8	−0.112	0.791	0.816
PSS10–PWB18	Perceived helplessness	Positive interpersonal relationships	7	−0.309	0.500	0.734
PSS10–PWB18	Perceived helplessness	Purpose in life	8	0.609	0.109	0.407
PSS10–PWB18	Perceived helplessness	Self-acceptance	8	−0.250	0.550	0.734
PSS10–MBI	Lack of self-efficacy	Depersonalization	9	0.112	0.775	0.775

(*Cont'd...*)

Table 2. (*Continued*)

Construct pair	Variable 1	Variable 2	*n*	Spearman's *rho*	*p*	*p*FDR
PSS10–MBI	Lack of self-efficacy	Emotional exhaustion	9	0.267	0.487	0.775
PSS10–MBI	Lack of self-efficacy	Personal accomplishment	9	−0.291	0.447	0.775
PSS10–MBI	Perceived helplessness	Depersonalization	9	0.159	0.683	0.775
PSS10–MBI	Perceived helplessness	Emotional exhaustion	9	0.212	0.584	0.775
PSS10–MBI	Perceived helplessness	Personal accomplishment	9	−0.392	0.296	0.775
PSS10–CASE	Lack of self-efficacy	CASE total score	9	0.090	0.818	0.878
PSS10–CASE	Lack of self-efficacy	Interpersonal physical/psychological abuse	9	−0.060	0.878	0.878
PSS10–CASE	Lack of self-efficacy	Neglect	9	0.531	0.141	0.211
PSS10–CASE	Perceived helplessness	CASE total score	9	0.790	0.011	0.036*
PSS10–CASE	Perceived helplessness	Interpersonal physical/psychological abuse	9	0.786	0.012	0.036*
PSS10–CASE	Perceived helplessness	Neglect	9	0.638	0.065	0.129
PWB18–MBI	Autonomy	Depersonalization	8	−0.532	0.175	0.716
PWB18–MBI	Autonomy	Emotional exhaustion	8	0.634	0.092	0.716
PWB18–MBI	Autonomy	Personal accomplishment	8	0.333	0.420	0.814
PWB18–MBI	Environmental mastery	Depersonalization	8	−0.242	0.563	0.890
PWB18–MBI	Environmental mastery	Emotional exhaustion	8	−0.098	0.818	0.890
PWB18–MBI	Environmental mastery	Personal accomplishment	8	0.406	0.318	0.716
PWB18–MBI	Personal growth	Depersonalization	8	−0.128	0.763	0.890
PWB18–MBI	Personal growth	Emotional exhaustion	8	−0.053	0.901	0.901
PWB18–MBI	Personal growth	Personal accomplishment	8	0.426	0.292	0.716
PWB18–MBI	Positive interpersonal relationships	Depersonalization	7	−0.138	0.769	0.890
PWB18–MBI	Positive interpersonal relationships	Emotional exhaustion	7	0.119	0.799	0.890
PWB18–MBI	Positive interpersonal relationships	Personal accomplishment	7	0.342	0.452	0.814
PWB18–MBI	Purpose in life	Depersonalization	8	0.671	0.069	0.716
PWB18–MBI	Purpose in life	Emotional exhaustion	8	−0.193	0.648	0.890
PWB18–MBI	Purpose in life	Personal accomplishment	8	−0.587	0.126	0.716
PWB18–MBI	Self-acceptance	Depersonalization	8	−0.453	0.259	0.716
PWB18–MBI	Self-acceptance	Emotional exhaustion	8	−0.085	0.841	0.890
PWB18–MBI	Self-acceptance	Personal accomplishment	8	0.430	0.287	0.716
PWB18–CASE	Autonomy	CASE total score	8	0.456	0.257	0.577

(*Cont'd...*)

Table 2. (*Continued*)

Construct pair	Variable 1	Variable 2	*n*	Spearman's *rho*	*p*	*p*FDR
PWB18–CASE	Autonomy	Interpersonal physical/psychological abuse	8	0.252	0.548	0.761
PWB18–CASE	Autonomy	Neglect	8	0.741	0.036	0.230
PWB18–CASE	Environmental mastery	CASE total score	8	−0.646	0.084	0.252
PWB18–CASE	Environmental mastery	Interpersonal physical/psychological abuse	8	−0.605	0.112	0.288
PWB18–CASE	Environmental mastery	Neglect	8	−0.727	0.041	0.230
PWB18–CASE	Personal growth	CASE total score	8	−0.229	0.586	0.761
PWB18–CASE	Personal growth	Interpersonal physical/psychological abuse	8	−0.040	0.925	0.979
PWB18–CASE	Personal growth	Neglect	8	−0.731	0.039	0.230
PWB18–CASE	Positive interpersonal relationships	CASE total score	7	−0.248	0.592	0.761
PWB18–CASE	Positive interpersonal relationships	Interpersonal physical/psychological abuse	7	−0.337	0.460	0.753
PWB18–CASE	Positive interpersonal relationships	Neglect	7	−0.391	0.386	0.753
PWB18–CASE	Purpose in life	CASE total score	8	0.646	0.084	0.252
PWB18–CASE	Purpose in life	Interpersonal physical/psychological abuse	8	0.704	0.051	0.230
PWB18–CASE	Purpose in life	Neglect	8	0.156	0.712	0.855
PWB18–CASE	Self-acceptance	CASE total score	8	−0.006	0.988	0.988
PWB18–CASE	Self-acceptance	Interpersonal physical/psychological abuse	8	0.049	0.908	0.979
PWB18–CASE	Self-acceptance	Neglect	8	−0.312	0.451	0.753
MBI–CASE	Depersonalization	CASE total score	9	0.039	0.920	0.920
MBI–CASE	Depersonalization	Interpersonal physical/psychological abuse	9	0.095	0.807	0.908
MBI–CASE	Depersonalization	Neglect	9	−0.108	0.783	0.908
MBI–CASE	Emotional exhaustion	CASE total score	9	0.253	0.511	0.908
MBI–CASE	Emotional exhaustion	Interpersonal physical/psychological abuse	9	0.128	0.742	0.908
MBI–CASE	Emotional exhaustion	Neglect	9	0.345	0.362	0.908
MBI–CASE	Personal accomplishment	CASE total score	9	−0.312	0.414	0.908
MBI–CASE	Personal accomplishment	Interpersonal physical/psychological abuse	9	−0.340	0.370	0.908
MBI–CASE	Personal accomplishment	Neglect	9	−0.318	0.405	0.908

Notes: *rho* = Spearman's rank correlation coefficient; *p* = unadjusted *p*-value; *p*FDR = *p*-value adjusted using the Benjamini–Hochberg FDR procedure within each predefined family of comparisons; *statistical significance after FDR correction (*p*FDR < 0.05); effective sample sizes vary across correlations because missing observations were handled pairwise.

Abbreviations: CASE: Caregiver Abuse Screen; FDR: False discovery rate; MBI: Maslach Burnout Inventory; PSS10: Perceived Stress Scale; PWB18: Psychological Well-Being Scale.

Table 3. Exploratory Spearman's rank-order correlations among psychological dimensions in volunteers

Construct pair	Variable 1	Variable 2	*n*	Spearman's *rho*	*p*	*p*FDR
PSS10–PWB18	Lack of self-efficacy	Autonomy	7	−0.648	0.116	0.199
PSS10–PWB18	Lack of self-efficacy	Environmental mastery	6	−0.880	0.021	0.112
PSS10–PWB18	Lack of self-efficacy	Personal growth	7	−0.170	0.716	0.716
PSS10–PWB18	Lack of self-efficacy	Positive interpersonal relationships	7	−0.654	0.111	0.199
PSS10–PWB18	Lack of self-efficacy	Purpose in life	6	−0.375	0.464	0.556
PSS10–PWB18	Lack of self-efficacy	Self-acceptance	7	−0.748	0.053	0.160
PSS10–PWB18	Perceived helplessness	Autonomy	7	−0.679	0.093	0.199
PSS10–PWB18	Perceived helplessness	Environmental mastery	6	−0.886	0.019	0.112
PSS10–PWB18	Perceived helplessness	Personal growth	7	−0.273	0.554	0.604
PSS10–PWB18	Perceived helplessness	Positive interpersonal relationships	7	−0.808	0.028	0.112
PSS10–PWB18	Perceived helplessness	Purpose in life	6	−0.530	0.280	0.373
PSS10–PWB18	Perceived helplessness	Self-acceptance	7	−0.577	0.175	0.263
PSS10–MBI	Lack of self-efficacy	Depersonalization	6	0.092	0.862	0.862
PSS10–MBI	Lack of self-efficacy	Emotional exhaustion	7	0.408	0.364	0.720
PSS10–MBI	Lack of self-efficacy	Personal accomplishment	7	−0.704	0.077	0.232
PSS10–MBI	Perceived helplessness	Depersonalization	6	−0.273	0.600	0.720
PSS10–MBI	Perceived helplessness	Emotional exhaustion	7	0.857	0.014	0.082
PSS10–MBI	Perceived helplessness	Personal accomplishment	7	−0.286	0.534	0.720
PSS10–CASE	Lack of self-efficacy	CASE total score	6	0.287	0.581	0.753
PSS10–CASE	Lack of self-efficacy	Interpersonal physical/psychological abuse	7	0.388	0.389	0.753
PSS10–CASE	Lack of self-efficacy	Neglect	6	0.254	0.627	0.753
PSS10–CASE	Perceived helplessness	CASE total score	6	0.270	0.604	0.753
PSS10–CASE	Perceived helplessness	Interpersonal physical/psychological abuse	7	0.000	1.000	1.000
PSS10–CASE	Perceived helplessness	Neglect	6	0.598	0.210	0.753
PWB18–MBI	Autonomy	Depersonalization	6	−0.188	0.722	0.918
PWB18–MBI	Autonomy	Emotional exhaustion	7	−0.753	0.051	0.458
PWB18–MBI	Autonomy	Personal accomplishment	7	0.624	0.134	0.535
PWB18–MBI	Environmental mastery	Depersonalization	5	0.447	0.450	0.810
PWB18–MBI	Environmental mastery	Emotional exhaustion	6	−0.600	0.208	0.535
PWB18–MBI	Environmental mastery	Personal accomplishment	6	0.600	0.208	0.535
PWB18–MBI	Personal growth	Depersonalization	6	0.123	0.816	0.918
PWB18–MBI	Personal growth	Emotional exhaustion	7	0.000	1.000	1.000
PWB18–MBI	Personal growth	Personal accomplishment	7	0.273	0.554	0.906
PWB18–MBI	Positive interpersonal relationships	Depersonalization	6	−0.161	0.760	0.918
PWB18–MBI	Positive interpersonal relationships	Emotional exhaustion	7	−0.906	0.005	0.088
PWB18–MBI	Positive interpersonal relationships	Personal accomplishment	7	0.394	0.382	0.763

(*Cont'd...*)

Table 3. (*Continued*)

Construct pair	Variable 1	Variable 2	*n*	Spearman's *rho*	*p*	*p*FDR
PWB18–MBI	Purpose in life	Depersonalization	5	−0.631	0.254	0.571
PWB18–MBI	Purpose in life	Emotional exhaustion	6	−0.706	0.117	0.535
PWB18–MBI	Purpose in life	Personal accomplishment	6	0.000	1.000	1.000
PWB18–MBI	Self-acceptance	Depersonalization	6	0.154	0.771	0.918
PWB18–MBI	Self-acceptance	Emotional exhaustion	7	−0.126	0.788	0.918
PWB18–MBI	Self-acceptance	Personal accomplishment	7	0.577	0.175	0.535
PWB18–CASE	Autonomy	CASE total score	6	−0.418	0.410	0.751
PWB18–CASE	Autonomy	Interpersonal physical/psychological abuse	7	−0.231	0.619	0.772
PWB18–CASE	Autonomy	Neglect	6	−0.554	0.254	0.751
PWB18–CASE	Environmental mastery	CASE total score	5	−0.707	0.182	0.654
PWB18–CASE	Environmental mastery	Interpersonal physical/psychological abuse	6	−0.309	0.552	0.772
PWB18–CASE	Environmental mastery	Neglect	5	−0.738	0.155	0.654
PWB18–CASE	Personal growth	CASE total score	6	0.783	0.065	0.588
PWB18–CASE	Personal growth	Interpersonal physical/psychological abuse	7	0.800	0.031	0.551
PWB18–CASE	Personal growth	Neglect	6	0.431	0.394	0.751
PWB18–CASE	Positive interpersonal relationships	CASE total score	6	−0.467	0.350	0.751
PWB18–CASE	Positive interpersonal relationships	Interpersonal physical/psychological abuse	7	−0.268	0.561	0.772
PWB18–CASE	Positive interpersonal relationships	Neglect	6	−0.635	0.175	0.654
PWB18–CASE	Purpose in life	CASE total score	5	−0.181	0.770	0.816
PWB18–CASE	Purpose in life	Interpersonal physical/psychological abuse	6	−0.095	0.857	0.857
PWB18–CASE	Purpose in life	Neglect	5	−0.406	0.498	0.772
PWB18–CASE	Self-acceptance	CASE total score	6	0.412	0.417	0.751
PWB18–CASE	Self-acceptance	Interpersonal physical/psychological abuse	7	0.170	0.716	0.805
PWB18–CASE	Self-acceptance	Neglect	6	0.243	0.643	0.772
MBI–CASE	Depersonalization	CASE total score	5	−0.057	0.927	0.949
MBI–CASE	Depersonalization	Interpersonal physical/psychological abuse	6	0.290	0.577	0.949
MBI–CASE	Depersonalization	Neglect	5	−0.054	0.931	0.949
MBI–CASE	Emotional exhaustion	CASE total score	6	0.439	0.383	0.949
MBI–CASE	Emotional exhaustion	Interpersonal physical/psychological abuse	7	0.056	0.905	0.949
MBI–CASE	Emotional exhaustion	Neglect	6	0.717	0.109	0.949
MBI–CASE	Personal accomplishment	CASE total score	6	−0.034	0.949	0.949
MBI–CASE	Personal accomplishment	Interpersonal physical/psychological abuse	7	−0.131	0.779	0.949
MBI–CASE	Personal accomplishment	Neglect	6	0.120	0.822	0.949

Notes: *rho* = Spearman's rank correlation coefficient; *p* = unadjusted *p*-value; *p*FDR = *p*-value adjusted using the Benjamini–Hochberg FDR procedure within each predefined family of comparisons; *statistical significance after FDR correction (*p*FDR < 0.05); effective sample sizes vary across correlations because missing observations were handled pairwise.

Abbreviations: CASE: Caregiver Abuse Screen; FDR: False discovery rate; MBI: Maslach Burnout Inventory; PSS10: Perceived Stress Scale; PWB18: Psychological Well-Being Scale.

detailed and specific analysis will be presented below for each theme and dimension that emerged, focusing on the aspects prevalent in the discourse.

The qualitative component drew on a different cohort from the quantitative sample. It was designed as a complementary analysis to broaden our understanding of the phenomenon by exploring caregivers' experiences. The two components were integrated at the interpretive level, emphasizing the complementarity of the evidence.

3.2.1. Themes

This section presents the themes that emerged from the analysis of the testimonies: disease onset, difficulties, medical examinations, coping, and needs.

(a) Disease onset

The theme related to the onset of the disease deals mainly with all those feelings and emotions reported by narrators at the time when ALS is discovered and later diagnosed. It is thus predominantly a theme typical of patients and family members. However, relevant aspects related to this theme also emerge in the narratives of FCs and volunteers.

When this theme emerges in the narratives of caregivers or volunteers, the reference is mainly to the possible physical, practical, and emotional impact of the diagnosis on the lives of patients and their families:

> *In questa condizione se la persona ha una scarsa elaborazione, con poche capacità introspettive, espressive e di insight, può vivere l'insorgenza della malattia come un'esperienza drammatica, al punto da compromettere l'integrità di sé, fino ad una condizione di estrema fragilità. È costretta, infatti, a riorganizzare l'immagine di sé, del proprio corpo e delle relazioni con l'ambiente e a dover fare i conti con una condizione dal decorso imprevedibile e a sostenere sintomi fisici di notevole importanza, accompagnati da vissuti di rabbia, paura, angoscia, vergogna e senso di colpa in particolare verso il familiare.*
>
> (In this condition, if the person has poor processing, with few introspective, expressive, and insight skills, he or she may experience the onset of illness as a dramatic experience, to the point of compromising the integrity of self, to a condition of extreme fragility. She is forced, in fact, to reorganize her self-image, her body image and her relationships with her environment and to come to terms with a condition with an unpredictable course and to sustain physical symptoms of considerable importance, accompanied by experiences of anger, fear, anxiety, shame and guilt particularly toward her family member).
>
> (IDnumber_00030)
>
> *Quando la SLA l'ha colpita, alcuni anni fa, la sua vita attiva e intensa tra scuola e famiglia, è stata ribaltata e si è dovuta adattare agli inevitabili cambiamenti cui il suo corpo la costringeva. Ha ridotto la sua attività, ha abbandonato la scuola e si è ritirata nella sua casa tra i suoi affetti di sempre.*
>
> (When ALS struck her a few years ago, her busy, active life between school and family was turned upside down, and she had to adapt to the inevitable changes to which her body was forcing her. She reduced her activities, dropped out of school, and retreated to her home among her lifelong affections).
>
> (IDnumber_00034)

The time of the disease's onset, however, can also be delicate for those caregivers, especially physicians, who must communicate the diagnosis to the patient and their family members. Here, then, the physician can experience a "*sensazione di sofferta impotenza* (feeling of suffering helplessness)" precisely because he is unable to do anything to improve the patient's condition:

> *Avrei voluto fare di più di una semplice visita. Si ha sempre l'impressione di non fare abbastanza di fronte a un malato di SLA. Forse perché sai benissimo che ha bisogno di tutto e tu puoi dargli tanto poco.*
>
> (I would have liked to do more than just visit. One always feels that one is not doing enough in front of an ALS patient. Maybe because you know very well that he needs everything and you can give him so little).
>
> (IDnumber_00085)

Finally, some narratives related to this topic remain more neutral and detached, and have a more rational tone, aimed at analyzing which aspects of ALS are known, and which are less, useful for increasingly early detection of the symptomatology associated with this disease:

> *Dobbiamo conoscere ancora molto della malattia. In particolare bisogna capire se la nota eterogeneità di manifestazioni cliniche è dovuta a cause e meccanismi differenti.*
>
> (We have yet to know much about the disease. In particular, we need to understand whether the known heterogeneity of clinical manifestations is due to different causes and mechanisms).

(IDnumber_00096)

(b) Difficulties

The theme related to the difficulties encountered at different stages of ALS is also more present in the accounts of patients and inFCs. However, as with the previous one, inFCs and volunteers talk a lot about it, mainly about the difficulties that patients and family members may face.

> *La SLA, infatti, è un evento critico che non colpisce solo chi ne porta i segni sul proprio corpo, ma tutta la famiglia, che si trova costretta a fronteggiare il disagio personale, relazionale e organizzativo che da essa deriva. In particolare ad essere leso è il caregiver, in cui si riscontra affaticamento fisico e mentale, non solo per l'elevato carico assistenziale da sostenere, ma anche per il dolore, la paura e il senso di impotenza, aggiunti magari a rivendicazioni radicate nel tempo o sensi di colpa che durano da anni. Inoltre, il perdurare della cura e la frequente presenza dei sanitari interrompono l'intimità familiare e trasformano l'ambiente fisico, i ritmi di vita e il clima all'interno della casa. La malattia impone, quindi, all'intera famiglia una riorganizzazione e un riadattamento concreti e simbolici, a seguito dei cambiamenti pratici, affettivi ed esistenziali che la malattia porta con sé.*
>
> (ALS, in fact, is a critical event that affects not only those who bear the signs of it on their bodies, but the whole family, which is forced to cope with the personal, relational and organizational discomfort that results from it. Particularly harmed is the caregiver, in whom there is physical and mental fatigue, not only because of the high caregiver burden to be borne, but also because of the pain, fear, and sense of helplessness, added perhaps to claims rooted in time or guilt that have lasted for years. In addition, the continuation of care and the frequent presence of caregivers interrupt family intimacy and transform the physical environment, living rhythms, and climate within the home. Thus, illness imposes concrete and symbolic reorganization and readjustment on the entire family as a result of the practical, affective, and existential changes that illness brings).
>
> (IDnumber_00030)

The difficulties that emerge in their narratives also focus on diagnosis and caregiving. Getting in touch with a patient, in fact, especially in the beginning, is difficult: "*era un disagio, passare tutta la giornata con una persona che non parla e parlare per due* (It was an inconvenience, spending the whole day with a person who does not speak, having to talk for two)." Therefore, one must set out to create an authentic and trusting relationship in which the patient can trust the caregiver and accept his or her support:

> *Per superare la barriera, stabilire un rapporto con Simonetta all'inizio le ho raccontato tutta (quasi) la mia vita, descritto i miei interessi, i miei valori. Pian piano la barriera si è sciolta e mi sono resa conto che Simo mi ha accettata.*
>
> (To overcome the barrier, to establish a relationship with Simonetta, at first I told her my whole (almost) life, described my interests, my values. Gradually the barrier dissolved and I realized that Simo accepted me).
>
> (IDnumber_00016)

Finally, on an emotional level, difficulties can also occur when the physician is, or has been, also an informal caregiver of a loved one who has had ALS. Here, then, although not working in specific ALS departments, the moment one is in the hospital faced with an ALS patient in need of medical intervention, memories resurface, and emotions take over. In this case, therefore, the personal story is mixed with the professional narrative, in a mix of emotions, feelings, and comparisons that increasingly diminish the distance between the past self as "daughter caregiver" and the current self as "doctor." When personal reality and professional reality meet, therefore, the difficulties seem to be greater, and one struggles to find a way out. One struggles to make a professional decision because personal emotions and memories take over. And one empathizes with family members and patients, wondering what is right for one and the other, but without finding an answer that seems best.

> La barella pigolante porta un lenzuolo, il corpo è così magro da non distinguersi. Accanto sulla barella, spinta dal portantino, la mano di quello che per me è un ragazzino […]
>
> "Mi scusi, mi hanno mandato qui con mia mamma per fare la tracheotomia"
>
> E che ne sa questo bambino di tracheotomia?
>
> Suona il telefono ed il collega della Terapia Intensiva Respiratoria si scusa per essersi dimenticato di avvertirmi che sarebbe arrivata dalla provincia una paziente con la SLA per fare la tracheotomia […]
>
> Non faccio in tempo a chiudere il telefono che sento freddo, io che sento freddo solo quando sono ammalata. Sento il cuore che se ne andato nella testa.

[…] "Ma quanti anni hai?" - "Ne ho fatti diciotto"

Sollevo il lenzuolo e vedo quello che ho visto anche io a venti anni. Mio padre è morto di SLA.

Uno scheletro ricoperto di una pelle rinsecchita, gli occhi due fossi, gli zigomi di fuori, i denti esposti. Lui che era stato un uomo corpulento con dei vivaci occhi blu. Immobile nella sua totale paralisi del corpo, l'unico movimento consentitogli dalla malattia aprire e chiudere le palpebre. Anche la parola gli aveva tolto la malattia, e da lì a poco, prima della morte, la possibilità di mangiare, lui così goloso, ed il respiro. Quello che la malattia non gli aveva tolto era la coscienza, poteva vivere il dolore del suo corpo e della mente, poteva vivere ogni giorno la difficoltà di farsi comprendere. Gli era difficile finanche piangere.

Quella madre era identica, solo i suoi occhi erano scuri come quelli di suo figlio.

[…]

NON SO CHE FARE.

"Ma la mamma voleva fatta la tracheotomia?" chiedo.

Nessuno le aveva detto come si muore di SLA, nessuno le aveva dato la possibilità di decidere.

Guardavo quel ragazzino. […]

Fare una tracheotomia e condannare quella donna a qualcosa che forse non avrebbe voluto.

Fare la tracheotomia e condannare un ragazzo alla stessa condanna di sua madre, una assistenza domiciliare quasi ventiquattro ore su ventiquattro, considerando la carenza cronica di strutture nella nostra isola. Condannarlo a lasciare la sua giovinezza per assistere per molto tempo una mamma con la tracheotomia, un respiratore artificiale, una sonda nella pancia per mangiare, con pannoloni da cambiare, senza un movimento, senza una parola, solo due palpebre da aprire e chiudere per comunicare e poi più neanche questo.

Ma la sua mamma avrebbe voluto sopravvire così divorando la vita di suo figlio?

Io mamma come lei lo vorrei?

[…] La SLA non perdona, è una malattia terminale.

Guardavo lei, semiaddormentata dall'insufficienza respiratoria, guardavo lui con quella valigetta con le cose della sua mamma.

AIUTO!!! NON VOGLIO, NON RIESCO, NON POSSO DECIDERE!!!

[…]

Si avvicina il mio collega pomeridiano che deve "darmi la smonta". Pensaci tu.

Io vigliacca lo lascio da solo, io che cerco sempre di condividere le scelte.

È il mio ultimo giorno, vado in ferie.

Non ho mai voluto sapere come era andata a finire.

(The lazy stretcher carries a sheet, the body is so thin that it cannot be distinguished. Next to it on the stretcher, pushed by the stretcher-bearer, the hand of what to me is a little boy [...]

"Excuse me, I was sent here with my mom to have a tracheotomy."

And what does this child know about tracheotomy?

The phone rings, and the Respiratory ICU colleague apologizes for forgetting to warn me that an ALS patient was coming from the province to do the tracheotomy [...]

I do not have time to hang up the phone when I start to feel cold, even though I only ever feel cold when I am sick. I feel my heart has moved up into my head.

[...] "But how old are you?" – "I am eighteen."

I lift the sheet and see what I also saw when I was twenty. My father died of ALS.

A skeleton covered with dried-up skin, eyes two ditches, cheekbones out, teeth exposed. He had been a burly man with vivid blue eyes. Motionless in his total body paralysis, the only movement allowed him by the disease was opening and closing his eyelids. Even speech had been taken from him by the disease, and shortly thereafter, before death, the ability to eat, he so gluttonous, and to breathe. What the disease had not taken away from him was consciousness; he could experience the pain of his body and mind, he could experience every day the difficulty of making himself understood. It was difficult for him even to cry.

That mother was identical, only her eyes were as dark as her son's.

[...]

DON'T KNOW WHAT TO DO.

"But did mother want to have a tracheotomy done?" I ask.

No one had told her how to die of ALS; no one had given her a chance to decide.

I was looking at that little boy. [...]

Doing a tracheotomy and condemning that woman to something she might not have wanted.

Doing a tracheotomy and condemning a boy to the same sentence as his mother, an almost around-the-clock home care, considering the chronic shortage of facilities on our island. Condemning him to leave his youth to care for a long time for a mom with a tracheotomy, an artificial respirator, a probe in her belly to eat, with diapers to change, without a movement, without a word, just two eyelids to open and close to communicate, and then not even that anymore.

But would her mom have wanted to survive like this by devouring her child's life?

Would I want to be a mother like her?

[...] ALS is unforgiving; it is a terminal disease.

I looked at her, half asleep from respiratory failure; I looked at him with that briefcase with his mom's things.

HELP!!! I DON'T WANT TO, I CAN'T, I CAN'T DECIDE!!!

[...]

My afternoon colleague who has to "give me the dismount" approaches. You take care of it.

I cowardly leave him alone, I who always try to share choices.

It's my last day; I'm going on vacation.

I never wanted to know how it had turned out).

(IDnumber_00109)

Through this testimony, it becomes clear how social and health workers are also emotionally involved in taking care of patients in different settings. Thus, the importance of thoroughly investigating these emotions, these difficulties, and these connections to one's history, which can lead to mixed feelings, during caregiving emerges.

(c) Medical examinations

The theme related to medical procedures and examinations is the one that, among FCs and volunteers, is the most neutral of all, unlike the narratives of patients and family members, where the associated emotionality also emerges in this topic.

When talking about this part, social workers focus on the strong impact on the patient's family life:

il perdurare della cura e la frequente presenza dei sanitari interrompono l'intimità familiare e trasformano l'ambiente fisico, i ritmi di vita e il clima all'interno della casa.

(the continuation of care and the frequent presence of caregivers interrupt family intimacy and transform the physical environment, living rhythms, and climate within the home).

(IDnumber_00030)

The fact that this purely medical topic is almost absent from the narratives of those who deal with the medical side daily prompts us to reflect. Could it be a topic that is taken for granted as being technical and therefore deemed of little importance when it comes to talking about ALS? Could it be that practitioners, researchers, physicians, and volunteers, in narrating ALS, want to give voice to the patients, thus focusing on telling life stories, episodes, and family implications of the disease? In order to answer these questions, it would be useful to address the issue in more depth by collecting other testimonies and narratives.

(d) Coping

The coping strategies implemented by FCs and volunteers are different from those used by patients and family members when faced with ALS. Emerging in these narratives is the importance of continuing to do research, especially at the genetic, clinical, and medical levels. The goal is precisely to "*analizzare, con metodo, questa eterogeneità* (analyze, methodically, this heterogeneity)" typical of ALS to identify the underlying causes, the genes involved, and test new drug therapies for treatment:

E con la disponibilità dei dati di malattia organizzati possiamo "dissezionare" la SLA nei tanti sottogruppi in cui essa si manifesta, con l'obiettivo di ricercare, fino a trovare, speriamo il primo possibile, delle soluzioni per ognuna di queste.

(And with the availability of organized disease data, we can "dissect" ALS into the many subgroups into which it manifests itself, with the goal of researching until we find, hopefully as soon as possible, solutions for each of these).

(IDnumber_00096)

Moreover, coping strategies may vary according

to the professionalism of the patient's caregiver and family member. The importance of psychological and psychotherapeutic interventions is emphasized for the support of the entire family unit. The importance of finding practical solutions for moving patients is also discussed: "*abbiamo deciso di realizzare il veicolo attrezzato per i malati di SLA* (we decided to make the vehicle equipped for ALS patients)." Body and mind, then, are two central elements in the vision of those who tell the story of ALS, from a formal point of view, in relation to coping and "survival" strategies.

(e) Needs

The last theme present in the different testimonies concerns needs. Needs of patients and family members, also present in the narratives of FCs and volunteers: "*le parole di incoraggiamento, le riflessioni degli amici ammalati per supportarsi reciprocamente ed essere più forti della malattia stessa* (the words of encouragement, the reflections of sick friends to support each other and be stronger than the disease itself)."

> *La malattia causa spesso una sofferenza globale, non solo fisica (perché i muscoli sono contratti), ma anche psicologica, perché col progredire delle disabilità si modifica la percezione ed il riconoscimento di sé e matura la consapevolezza di stare andando incontro alla morte.*
>
> (The disease often causes global suffering, not only physically (because muscles are contracted), but also psychologically, because as the disabilities progress, the perception and recognition of self change and the awareness that one is going to death matures).
>
> (IDnumber_00103)

However, these practitioners also struggle, albeit in different ways, with this disease every day. The primary need is precisely that of "*far parte di squadra nella lotta contro questa brutta malattia come SLA* (to be part of a team in the fight against this ugly disease as ALS)" to feel less alone and stronger in seeking and taking care of patients and their families. It is precisely this aspect that strongly emphasizes the importance of the implementation of multiprofessional teams, composed of different professionals (and also volunteers) who have the common goal of the comprehensive care of the patient and his or her family, but who have different looks and skills that can be integrated with each other.

Another need that emerges relates to the more emotional aspect involved in caregiving, which manifests itself especially when the patient passes away, as well described in this testimony: "*superare i momenti più dolorosi nel regresso e scomparsa della mia cara Simonetta* (overcome the most painful moments in the regress and disappearance of my dear Simonetta)."

Finally, in common with patients and informal caregivers, FCs and volunteers also feel the need to "*far capire cosa significhi essere malati di SLA, quali rinunce, quali sofferenze e a quali scelte anticipate porti la malattia* (make people understand what it means to be sick with ALS, what renunciations, what suffering, and what early choices the disease leads to)." The eye, therefore, seems to be focused, once again, not only on medical and practical needs, but also on emotional and psychological ones, from a perspective that integrates the patient and his or her family.

3.2.2. Dimensions

This section presents the dimensions that emerged from the analysis of the testimonies: disease management, assistance, support, and effort.

(a) Disease management

The first implicit dimension in ALS testimonies concerns the management of ALS and includes all those aspects that change from the onset of ALS onward, and which must be managed as best as possible. Disease management can be emotional and physical. These two dimensions must be balanced, so as not to fall into alienation of the patient or his/her psychological vulnerability and dependence.

What emerges from these narratives is mainly the management of the disease to which patients and family members are called upon, as seen from the perspective of caregivers. This view focuses heavily on the consequences of ALS as a "*evento critico* (critical event)" that impacts the entire family:

> *[…] tutta la famiglia, che si trova costretta a fronteggiare il disagio personale, relazionale e organizzativo che da essa deriva. In particolare ad essere leso è il caregiver, in cui si riscontra affaticamento fisico e mentale, non solo per l'elevato carico assistenziale da sostenere, ma anche per il dolore, la paura e il senso di impotenza, aggiunti magari a rivendicazioni radicate nel tempo o sensi di colpa che durano da anni. Inoltre, il perdurare della cura e la frequente presenza dei sanitari interrompono l'intimità familiare e trasformano l'ambiente fisico, i ritmi di vita e il clima all'interno della casa. La malattia impone, quindi, all'intera famiglia una riorganizzazione e un riadattamento concreti e simbolici, a seguito dei cambiamenti pratici, affettivi ed esistenziali che la malattia porta*

con sé.

([…] the entire family, which is forced to cope with the personal, relational and organizational distress that comes with it. Particularly harmed is the caregiver, in whom there is physical and mental fatigue, not only because of the high caregiver burden to be borne, but also because of pain, fear and a sense of helplessness, added perhaps to claims rooted in time or guilt that have lasted for years. In addition, the continuation of care and the frequent presence of caregivers interrupt family intimacy and transform the physical environment, living rhythms, and climate within the home. Thus, illness imposes concrete and symbolic reorganization and readjustment on the entire family as a result of the practical, affective, and existential changes that illness brings).

(IDnumber_00030)

Then once again the issue of disease management through drugs returns, especially in the trial mode, an aspect emphasized by practitioners and researchers: "*Ed è una malattia per la quale al momento non esiste una terapia risolutiva, ma solo sperimentazioni di farmaci* (And it is a disease for which there is currently no cure-all therapy, only drug trials)."

(b) Assistance

The second dimension concerns all those aspects that ALS patients and caregivers need to cope with the lowest possible level of suffering with all that ALS entails, and thus to have an acceptable QoL: technological and relational assistance. Again, these two dimensions must be balanced, so as not to fall into the patient's dehumanization or his/her opposition to medical and technical cure.

Social and healthcare workers, researchers, and volunteers perceive the importance of technological assistance through the aid of the correct instrumentation, so they acquire the skills through specific training courses, which enable them to learn "*le basi principali dell'assistenza e gestione dell'attrezzatura (ventilatore, aspiratore, impianto alimentazione* (the main basics of equipment servicing and management [fan, vacuum, power system])."

They also perceive and report, in addition, the importance of relational care for the patient and his or her family, through the cooperation of the different professional figures with the different family members:

Cosi abbiamo cominciato a dipingere insieme alzando Simo dal letto, a leggere i libri, a guardare le foto dei loro viaggi con la famiglia, con il marito, a fare anche decoupage, che ho imparato per Simo quando lei non riusciva più a dipingere, ma mettere la colla per decoupage – si.

La fiducia cresceva e la comprensione reciproca anche.

(So we started painting together by getting Simo out of bed, reading books, looking at photos of their travels with their family, with their husband, even doing decoupage, which I learned for Simo when she could no longer paint, but put decoupage glue on – yes.

Trust grew and mutual understanding also).

(IDnumber_00016)

(c) Support

The third ALS dimension concerns social and self-directed support perceived as essential elements of comprehensive care for the ALS patient and his or her family. Within the testimonies of the FCs and volunteers, what emerges above all is the need for support that they believe the different family units in which an ALS patient is present need. One example is medical support, but also psychotherapeutic support. Their narratives, therefore, are more other-oriented (patient and family) rather than outlining the support they feel they themselves need, both personally and professionally:

l'avanzamento della malattia si fa spazio tra le parole di incoraggiamento, le riflessioni degli amici ammalati per supportarsi reciprocamente ed essere più forti della malattia stessa. Vanno avanti insieme a Luciana: raccontano le loro giornate intense e faticose, raccontano i loro affetti, le loro paure e delusioni.

(The advancement of the disease makes room for words of encouragement, reflections from sick friends to support each other and be stronger than the disease itself. They move forward together with Luciana: they recount their intense and tiring days, tell of their affections, fears, and disappointments).

(IDnumber_00034)

(d) Effort

Finally, the fourth implicit dimension includes the effort: all the institutional and personal, physical, emotional, and social actions to be put in place to fight against ALS. Significant, in identifying the effort to be put forth in the "war" against disease, is the testimony of this FC in remembering a dear patient:

Il silenzio a volte urla e quel giorno mi ha

trasmesso la voglia di continuare ad andare avanti e a lottare. Le lacrime non riesco a trattenerle. Sono per Nicola, ma anche per Pietro, per Angelica, per Anna, per Vincenzo…per tutti quelli che ci hanno lasciato dentro la convinzione che tutto si può fare meno che lasciarsi sopraffare dalla SLA.

Così indosso ancora una volta la mia divisa da soldato Ryan, sperando di poter tornare un giorno a casa e di portare con me tutti i malati di SLA finalmente guariti e le loro famiglie.

E rendo onore ad un altro grande guerriero che porteremo sempre nel cuore.

(Silence sometimes screams, and that day conveyed to me the will to keep going and fighting. The tears I cannot hold back. They are for Nicola, but also for Pietro, for Angelica, for Anna, for Vincenzo...for all those who have left us with the conviction that anything can be done, except letting ALS overwhelm us.

So I wear my uniform once again as Private Ryan, hoping to one day return home and take with me all the ALS patients who have finally been cured and their families.

And I honor another great warrior whom we will always carry in our hearts).

(IDnumber_00085)

In addition to the research effort discussed above, there thus emerges the importance, even for those not directly affected by ALS, of bringing all their resources to support and share them, so that the effort from the personal side becomes generalized and institutional. This balance is important to ensure that inequality, fragmentation, or passivity toward the health care system does not emerge.

4. Discussion

This study aimed to analyze what it means to be a FC or a volunteer for ALS patients, focusing on the effects, both positive and negative, on QoL, stress, burden, and caregiving capacity. We examined these aspects thanks to Villa dei Cedri and to all the people who published their stories of caregiving online.

Regarding Villa dei Cedri's results, no significant differences were found across psychological variables between FCs and volunteers. However, given the small sample size, the absence of statistically significant differences should not be interpreted as evidence of equivalence between the two groups. The small sample size represents a limitation of this study; therefore, our future aim is to increase the study population to make deeper comparisons. Regarding perceived stress, both groups showed moderate levels, including specific sub-dimensions related to feelings of lack of control, emotional reactions, interpersonal relationships, and perceived coping ability, aligning with average levels in the general population. Both groups also displayed high psychological well-being across six subscales, typical of self-assured, independent individuals who can resist social pressures, regulate behavior, and set personal standards. They effectively manage their environment and show high scores in personal growth, indicating ongoing development and openness to change, which fosters self-awareness. Their relationships are built on trust, empathy, and intimacy, with clear life goals and meaningful interpretation of past and present experiences. These consistent findings show low levels of burnout dimensions in emotional exhaustion and depersonalization, and moderate personal accomplishment, suggesting a lower risk of emotional coldness or disinterest toward patients. They maintain a moderate to high perception of competence and desire for success, thus lessening burnout risk. However, these results differ from studies on FCs of chronic disease patients, where illness often negatively impacts well-being and QoL, especially with prolonged treatment.[22,23] One possible interpretation of the relatively favorable well-being, stress, and burnout profiles may concern the specific characteristics of the work setting and the end-of-life care context. However, these factors were not directly assessed in the present study, and their potential contribution cannot be inferred from the current data. Future studies should specifically investigate whether characteristics of the care setting may contribute to these psychological outcomes. Nonetheless, further research with a larger sample is necessary to confirm these hypotheses. Notably, a small portion of FCs approach the risk threshold for abusive behaviors, with three FCs and one volunteer at significant risk of neglect or physical and psychological abuse. Given the small sample size, further research is needed on this finding to better understand its implications. These findings highlight the importance of further investigating psychological factors potentially associated with CASE scores, while avoiding causal interpretations based on the present cross-sectional data. This emphasizes the importance of monitoring perceived stress, especially in interactions with patients, to prevent potential abuse. After correction for multiple comparisons using the Benjamini–Hochberg FDR procedure, three statistically significant associations remained among FCs. Higher perceived helplessness was associated with lower environmental mastery and with higher overall CASE scores and interpersonal physical/psychological

abuse scores. These associations should be interpreted cautiously and considered exploratory and hypothesis-generating rather than evidence of causal relationships. For volunteers, none of the examined correlations remained statistically significant after FDR correction. Nevertheless, two associations showed a trend toward statistical significance: higher perceived helplessness tended to be associated with greater emotional exhaustion, while more positive interpersonal relationships tended to be associated with lower emotional exhaustion. Given the small sample size, these trends should be interpreted cautiously as preliminary signals requiring confirmation in larger samples. No prior research has examined the well-being, stress, burnout, or QoL of volunteer caregivers for ALS patients, highlighting the preliminary nature of these findings and the need for future studies. No differences emerged between groups across psychological variables, but limited participation of foreign subjects prevented a thorough analysis of nationality effects. The findings are preliminary and exploratory; further data collection will include other Lombard region units, with additional ethical approval, to increase the sample size and to assess whether these preliminary findings can be replicated across different social, health, and care contexts as well. Furthermore, a future research goal could be to develop and validate predictive models capable of identifying the main risk factors associated with risky behaviors, with potential implications for screening and early prevention interventions. Such models would require substantially larger samples and independent validation. This will enable more detailed investigation of ALS-related caregiving challenges and support strategies to improve caregivers' QoL and well-being.

In terms of discursive modes, many testimonies incorporate an emotional component that is conveyed to the reader. However, there are also more rational segments wherein it becomes evident what, beyond emotional reactions, ALS entails concerning needs, efforts, care, and management.[21,49] An illustration of this can be observed, particularly when FCs talk about ALS patients, but they also include some personal flashbacks or emotive considerations on the situation imposed on the ALS patient and his or her family. Through these testimonies, when recounting their experiences with ALS, FCs and volunteers tend to emphasize technical aspects, including diagnosis, examinations, and supportive technology. Furthermore, issues relevant to this group also include the needs and desires encountered within their interactions with patients and families. However, little is revealed regarding their personal experiences and emotional responses to this condition. Consequently, it would be beneficial to conduct further studies to explore the perceptions and experiences of these professional or volunteer caregivers in caring for ALS patients. In conclusion, this study has facilitated an exploration of the multifaceted issues and meanings associated with ALS, a subject still relatively understudied. The analysis permitted a comprehensive examination of the intricate details emerging from the narratives, aimed at fostering a deeper understanding of the thoughts and feelings of those who confront ALS daily. The number of testimonies spontaneously provided by professional caregivers and volunteers could be expanded to identify whether additional significant aspects may emerge within this group that have not yet been highlighted.

The results of both research studies presented here, although conducted with different methodologies and in different contexts, emphasize the crucial role of context, both physical and symbolic, in supporting professional or volunteer figures involved in caring for people with ALS.

However, this approach implies that the qualitative findings cannot be directly generalized to the quantitative sample, and vice versa, but must be interpreted as a contribution aimed at deepening and contextualizing the overall results of the study.

In general, the results of the study conducted in collaboration with Villa dei Cedri raise the hypothesis of a possible positive influence of the natural environment present in the work setting on burnout, perceived stress, and psychological well-being among FCs and volunteers.[49,50] However, the natural environment was not directly assessed in the present study; therefore, a protective effect cannot be inferred from the current findings. Whether there is a potential protective effect of the environment on the mental health of social-health workers and volunteers working in this setting, in contact with serious illnesses such as ALS, should therefore be further investigated through studies specifically designed to assess environmental characteristics and their relationship with psychological outcomes. At the same time, the analysis of the spontaneously produced online testimonies shows that there is a strong dedication and continuity in the fight against the disease, even when there is no (more) direct involvement. These narratives not only describe the difficulties and needs faced by patients and family members as seen through the eyes of FCs and volunteers, but also talk about coping strategies, altruistic motivations, and a collective vision of caring for each other. In this sense, the integration of a supportive environmental context and a network of shared meanings through narrative production emerges as a central element in promoting well-being and resilience of FCs and volunteers, helping to mitigate the risks associated with their burnout and dysfunctional behaviors.[50,51] The present study did not directly assess

whether these factors mitigate burnout or dysfunctional behaviors; therefore, such a protective role cannot be inferred from the current findings. Given these findings, it would be prudent to pursue further research, such as conducting interviews and focus groups involving FCs and volunteers to attain a more nuanced understanding of their experiences within the socio-cultural context of their production. Future studies could also directly investigate whether environmental characteristics and shared narrative meanings are associated with psychological well-being, resilience, burnout, and dysfunctional or abusive behaviors. Only in this way will it be possible to structure training and support programs within different work contexts that consider both personal characteristics and those of the work environment, with the overall goal of increasing personal and professional skills and promoting the well-being of the FC and volunteer.

5. Conclusion

Overall, the two studies provide an initial exploration of the psychological dimensions and experiences of caring for people with ALS among FCs and volunteers. While participants generally exhibited good psychological well-being and a low risk of burnout, certain findings, particularly those concerning perceived helplessness and its correlation with specific psychological and behavioral indicators, require further investigation. At the same time, online testimonials show that FCs and volunteers primarily describe the caregiving experience in terms of the needs of people with ALS and their families, daily caregiving aspects, and motivations related to care. The personal emotional experiences of FCs and volunteers are less explicitly addressed.

Given the preliminary and exploratory nature of these findings, future studies involving larger sample sizes and conducted in different care settings are required to further investigate these aspects and improve the understanding of the personal, relational, and contextual factors influencing the well-being of individuals providing care to people with ALS, whether through employment or volunteering.

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Ethics approval and consent to participate

For the first part of the study, conducted in Villa dei Cedri, the research was approved by the Lombardy 2 Regional Ethics Committee at its meeting on December 11, 2024 (protocol code: L2-270). The research was also conducted following the ethical principles outlined in the Declaration of Helsinki. Each participant included in the study provided their informed consent to participate in the research and to be published.

For the second part of the study, conducted on online testimonies, this is a study that does not directly involve people but analyzes testimonies spontaneously produced and voluntarily posted online, accessible to anyone with an Internet connection. Since no participants were recruited, and no sensitive information is present, the study does not require ethical approval. Following a preliminary review conducted via the platform of the Committee for Integrity and Research Ethics of the University of Bergamo, the research project was deemed "not applicable" for evaluation by the Committee, as (to quote the response received) it does not present any ethical or legal issues that require a formal opinion. This outcome is consistent with the terms of the Regulations of the Committee for Integrity and Research Ethics of the University of Bergamo (Article 3, paragraph 1, letter a, and paragraph 2), which establish that only research involving individuals and/or with significant ethical implications is subject to ethical evaluation, excluding activities that do not implicate the direct involvement of human subjects, the use of sensitive personal data or experimental interventions, and research that takes the form of literature reviews or theoretical and methodological analyses. This regulation also complies with the Regulation of the Territorial Ethics Committees of the Lombardy Region (Articles 3 and 4), which identifies the competences of the Territorial Ethics Committees in the evaluation of clinical trials, observational studies, pharmacological studies, and research involving different types of interventions and research that actively involve people. Therefore, in light of the official outcome of the preliminary review and the current regulatory framework, we can confirm that the project does not need to be evaluated by the Ethics Committee. However, the research

was conducted following the ethical principles outlined in the Declaration of Helsinki, and written testimonies were posted online anonymously.

Consent for publication

All involved participants accepted the written informed consent to participate and to publish the data in anonymized form.

Availability of data

The data supporting the findings of this study were derived from a larger research project and are not publicly available. However, they may be made available from the corresponding author upon reasonable request.

AI tools statement

Grammarly free version (v1.2.276.1919, Grammarly, Inc., USA) was used after the manuscript had been fully drafted, for lexical and grammatical review. After that, the grammatical corrections were manually verified by the authors for accuracy and originality. AI was not involved in study design, data analysis/interpretation, or conclusion drawing.

Further disclosure

Part of or the entire set of findings has been presented few conferences. Zambetti, E., Baronchelli, I., Belli, S., Mucci, C., & Greco, A. (2026). Being ALS patient's formal or informal caregiver: preliminary results on healthcare workers'and familiars' psychological well-being. 31st International Congress of Applied Psychology. July 21–25, 2026, Florence, Italy; Zambetti, E., Belli, S., Mucci, C., & Greco, A. (2025). "We are stronger than ALS". An emotional and narrative insight of patients' and caregivers' testimonies using a mixed-methods approach. [paper abstract n. 331765]. *10th World Conference on Qualitative Research. Madrid*. ISBN: 978-65-80968-52-7. https://proceedings.science/wcqr-2026/papers/we-are-stronger-than-als-an-emotional-and-narrative-insight-of-patients-and-care?lang=en. January 20–22, 2026, Complutense University of Madrid, Spain; Zambetti, E., Baronchelli, I., Belli, S., Mucci, C., & Greco, A. (2025). Working with suffering: stress, burnout and psychological well-being in Amyotrophic Lateral Sclerosis patients' formal caregivers. *E-book of Abstracts. ADAPT International Conference 2025. WORK AND NON-WORK, TODAY. Reframing the Issue Through an Interdisciplinary Perspective. XV edition. (pp. 353-354)*. Bergamo. https://www.adaptuniversitypress.it/wp-content/uploads/2025/09/2025_ebook_of_abstract.pdf. November 26–28, 2025, ADAPT International School of Higher Education in Labor and Industrial Relations, Bergamo, Italy; Zambetti, E., Baronchelli, I., Belli, S., Mucci, C., & Greco, A. (2025). Caregivers in Amyotrophic Lateral Sclerosis: preliminary results between paid care and family care. *E-book of Abstracts. ADAPT International Conference 2025. WORK AND NON-WORK, TODAY. Reframing the Issue Through an Interdisciplinary Perspective. XV edition. (pp. 351-351)*. Bergamo. https://www.adaptuniversitypress.it/wp-content/uploads/2025/09/2025_ebook_of_abstract.pdf. November 26–28, 2025, ADAPT International School of Higher Education in Labor and Industrial Relations, Bergamo, Italy; Zambetti, E., Baronchelli, I., Manzoni, P., Mucci, C., & Greco, A. (2025). Il benessere psicologico nei caregiver formali dei pazienti SLA. Il risvolto emotivo della cura. *Libro degli Atti. XV Congresso Nazionale SIPSA*. Psicologia per la Salute: Intersezioni, Unicità, Equità e Sostenibilità. (pp. 47). Torino. June 4–7, 2025, Italian Society of Health Psychology, Turin, Italy.

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