

Living with Amyotrophic Lateral Sclerosis: Exploring what matters to patients and caregivers through their experiences

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Abstract

Background: Amyotrophic Lateral Sclerosis (ALS) is a rare neurodegenerative disease the causes of which are not fully understood, that leads to early death. From the diagnosis, ALS significantly impacts the quality of life (QoL) for patients and their caregivers due to its unique characteristics. Both patients and their caregivers, formal and informal, increasingly feel the need to share their experiences, communicate their needs, and talk about what living with ALS entails. **Objectives:** Given the few studies available in the literature on this topic, the study's aim is to explore the significance of ALS for patients and caregivers through their testimonies and to identify the collective representations and symbolic categories that influence their lives. **Design and Methods:** A total of 118 spontaneous written texts (67 produced by women) (81.752 tokens, TTR index=0.145; H% index=54.6%) collected from the web, from 67 ALS patients, 41 informal and 10 formal caregivers, were analyzed using the Emotional Text Mining (ETM) technique, with the T-Lab Software. **Results:** Four communication axes were identified: management of the disease (34.25%; physical vs. emotional), care (26.58%; technological vs. relational), support (21.39%; self-directed vs. social), and effort (17.78%; personal and institutional). The five clusters positioned in this factorial space relate to disease onset (12.29%), difficulties (30.78%), medical examinations (29.39%), coping strategies (14.79%), and needs (18.75%). There are differences between genders and groups. **Conclusion:** The interpretation of the results enables an understanding of the cultural-symbolic system of ALS patients and caregivers, as well as the impact of the disease on their QoL. Through this, personalized interventions can be designed to promote resources and psychological well-being.

Plain Language Summary

Background: Amyotrophic Lateral Sclerosis (ALS) is a rare, neurodegenerative disease with unknown causes, leading to early death. From diagnosis, ALS significantly impacts the quality of life (QoL) of both patients and caregivers, who increasingly want to share their experiences, communicate their needs, and discuss living with the condition. **Objectives:** There are few studies on this topic. This study explores the significance of ALS for patients and caregivers through testimonies and identifies the representations and categories that influence their lives. **Design and Methods:** A total of 118 spontaneous written texts (67 produced by women) (81.752 tokens, TTR index=0.145; H% index=54.6%) collected from the web, from 67 ALS patients, 41 informal and 10 formal caregivers, were analyzed using the Emotional Text Mining (ETM) technique, with the T-Lab Software. **Results:** There are four communication axes: management of the disease (34.25% physical vs. emotional), care (26.58% technological vs. relational), support (21.39% self-directed vs. social), and effort (17.78% personal and institutional). The five clusters positioned in this factorial space relate to disease onset (12.29%), difficulties (30.78%), medical examinations (29.39%), coping strategies (14.79%), and needs (18.75%). There are differences between genders and

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groups. **Conclusion:** Interpreting the results helps to understand ALS patients' and caregivers' cultural and symbolic needs, and the impact of the disease on their quality of life. This information can be used to create personalised support plans to help with resources and well-being.

Keywords

Amyotrophic Lateral Sclerosis, emotional text mining, testimonies, patients, caregivers, quality of life

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1. Background

Amyotrophic Lateral Sclerosis (ALS) is a rare, heterogeneous, and neurodegenerative disease without a cure that leads to death in about 5 years,^{1–3} the causes of which are not fully understood. Living with ALS can be devastating, affecting both physical and psychological aspects due to the progressive loss of autonomy in daily activities, the increasing need for assistance, and significant respiratory, feeding, and swallowing issues. In particular, ALS affects motor neurons, the nerve cells responsible for controlling voluntary movements,^{4,5} causing their progressive degeneration and death, resulting in a loss of muscle tone and strength.^{1,4} Early symptoms are often associated with weakness in the upper or lower limbs, difficulty with fine motor skills, or speech problems.⁴ As ALS progresses, symptoms worsen and manifest as increasing difficulty in performing common daily activities, such as walking, grabbing objects, or maintaining a stable posture,⁴ eventually leading, in the most advanced stages, to impairment of vital functions such as eating and breathing.⁶ Despite physical deterioration, sensory abilities and, in many cases, cognitive abilities remain initially intact, although some patients may develop cognitive and behavioral changes.^{5,7} Currently, there is no definitive cure, but various treatments are available that can slow degeneration and improve the patient's quality of life^{4,8,9}; a multidisciplinary approach is essential in the management of patients with ALS. In particular, nutritional management is important for preventing weight loss and maintaining the patient's energy status,^{6,10} while respiratory support, such as the use of non-invasive ventilation, becomes crucial in advanced stages to sustain vital and respiratory functions.^{11–13} Early and integrated care for the patient, as well as for their caregivers, is therefore a key element in managing life with ALS. Psychological and physical difficulties, in fact, have a profound impact on the quality of life (QoL) of patients and caregivers.⁸ Challenges in communication and social interactions, combined with physical difficulties, significantly diminish ALS patients' ability to engage socially and participate in everyday life.¹⁴ Therefore, it is essential to consider how these challenges affect their psychological well-being and overall QoL.¹⁵ Depression and anxiety often arise as consequences of understanding the rapid decline associated with the disease, leading to early death,^{16–18} which is another psychological factor to consider.¹⁹ Similar challenges have also been observed in other neurodegenerative disorders of the motor system, such as Huntington's disease and Parkinson's disease. In Huntington's disease, for example, the distress experienced by patients is also strongly influenced by genetic factors and the anticipation of the disease,²⁰ while in Parkinson's disease, uncertainty and stigma play a central role in patients' experiences.^{21,22} These factors can help us understand the psychological impact of various factors on ALS.

Moreover, caring for ALS patients can profoundly impact caregivers' lives, both within the family and in facility settings.^{23–25} After an ALS diagnosis, family members must undergo a complete reorganization of their family structure and identify those taking on the new caregiver role. This adjustment frequently leads to difficulties in their psychological and social well-being and QoL, particularly concerning the new ALS challenges.²³ In advanced stages of the disease, patients require specific care, often resulting in their admission to a residential facility where formal caregivers take care of them.²⁶ Formal caregivers are people who are paid to care for a patient.²⁶ ALS also affects their QoL and psychological well-being,^{24,27} as seen in other chronic diseases.^{27–30}

Key issues in patients' and caregivers' QoL relate to uncertainty about their "new life" and the disease's progression until death,^{18,19} particularly since ALS is incurable.^{18,31} They also frequently face feelings of injustice about their imposed life with the disease and experience physical and psychological loneliness.^{18,19} Many patients feel guilty for burdening their families who adjust their lives to provide care.¹⁸ However, some report positive aspects, like motivation to find meaning in life despite illness, helping others, accepting their condition, and valuing small daily moments.^{18,19} Family members' stories reveal themes about the meaning of the disease, personal life changes, family dynamics, and societal relationships, as well as the need for practical and psychological support, and loneliness.^{25,31–37} Informal caregivers often sacrifice their needs for their ALS patients.³¹ Formal caregivers' testimonies mainly highlight priorities for patients and families.³⁸ Previous studies have explored specific experiences of patients and formal and informal caregivers concerning specific topics, as, for example, palliative care,³⁹ death and bereavement,⁴⁰ diagnosis delivery,⁴¹ nutritional behaviors and management,^{42,43} non-invasive ventilation,⁴⁴ and emotional distress and well-being.⁴⁵

However, these studies focus primarily on general experiential dimensions or specific stages of the disease course, without systematically analyzing the communication processes underlying these experiences. Furthermore, this research tends to be fragmented, focusing on individual aspects or specific actors involved in ALS. There is a lack of integrated analysis that simultaneously considers patients, informal caregivers, and formal caregivers, exploring emerging themes across the board and, above all, the socially constructed axes of communication, derived from personal and social experience, throughout the course of ALS. For these reasons, this study aims to explore the meaning of ALS for patients and caregivers to identify collective representations and symbolic categories, to provide targeted support, and to analyze the significance ALS holds for all stakeholders. Specific aims include understanding patients' and caregivers' experiences with the disease, impactful daily aspects, and physical, psychological, relational, social, and emotional needs and desires. Lastly, it aims to emphasize the importance of deepening knowledge of ALS beyond medical understanding to include psychological, emotional, and social dimensions. This study thus contributes to existing literature by integrating multiple perspectives within a multi-stakeholder analytical framework; furthermore, it focuses not only on the content of the experience but also on how this content is communicated and internalized; finally, it explores communication as a dynamic and central dimension in living ALS. In this sense, the study aims to provide a more systemic and relational view of the experience of ALS.

2. Methods

2.1. Design

This study is a qualitative, observational, exploratory, and documentary study based on a mixed qualitative-lexicometric analysis, using the Emotional Text Mining technique, of spontaneously generated online narratives derived from indirect data collection.

2.2. Data collection

A total of 118 Italian written testimonies were selected, between February 8, 2025, and April 30, 2025, from 38 (reaching saturation of the criteria necessary for a rigorous and reliable analysis with T-LAB Software according to the Emotional Text Mining technique.) publicly accessible websites related to associations (e.g., AISLA, *conSLAncio* Onlus), forums and blogs (e.g., *Il Blog di Sabino Paciolla*), online newspapers (e.g., State of Mind), and magazines (e.g., *ScriverEsistere*). Testimonies were included only if they were spontaneously produced, without an interview or an initial question to answer, and posted online in an open-access form. The online testimonials were collected through a structured web search conducted in Italian. The search was carried out on Google using combinations of keywords, including “*testimonianze SLA*” (“ALS testimonials”), “*esperienze Sclerosi Laterale Amiotrofica*” (“experiences Amyotrophic Lateral Sclerosis”), “*vivere con SLA*” (“living with ALS”), and other similar expressions. In parallel, a targeted exploration was conducted of the websites of Italian ALS associations and caregiver support organizations, which were considered authoritative sources. The texts were selected based on their relevance to lived experiences of ALS and the presence of narrative content sufficiently rich for textual analysis with the Emotional Text Mining Technique. The purpose of the collection was not to conduct a systematic review, but rather to build a qualitative corpus of spontaneous narratives.

The corpus included testimonials that met the following criteria: text written in Italian; texts explicitly referring to ALS; narratives published in publicly accessible online contexts (e.g., forums, blogs); testimonials attributable to patients, informal caregivers, or formal caregivers; narratives produced spontaneously, without prompting from third parties. The following were excluded: content not relevant to ALS or referring to other conditions; duplicate or redundant texts; messages that were too brief or lacked meaningful content (e.g., isolated sentences, monosyllabic comments); content that was predominantly informational, advertising, or promotional (e.g., popular science articles without an experiential component); texts with ambiguity regarding the author's role (not clearly attributable to a patient, caregiver, or healthcare professional).

Sixty-seven were ALS patients' testimonies, 41 were family members and/or friends (from now informal caregivers) experiences, and 10 were produced by other people directly involved in ALS care and research but do not have a close relationship connection with patients, like healthcare and social workers and/or researchers (from now formal caregivers). The narratives were equally distributed among women (56.78%; $n=67$) and men (43.22%; $n=51$). Testimonies already on the net were analyzed, given the difficulty of data collection involved in this field of research, especially about patients, given the peculiar characteristics of ALS.

The decision regarding the size of the corpus was guided by the adequacy indices provided by T-LAB (see the following sections), which indicated that the textual structure was sufficiently rich and diverse to support reliable and interpretable analyses; therefore, the number of testimonies included was deemed appropriate for the study.

2.3. Corpus preparation and data analysis

All 118 testimonies were coded with T-Lab Software^{46,47} string (e.g., **** *IDnumber_00001 *WHO_P *GEN_F) containing a progressive identifier of the narrative, gender (male or female), and group to which the testimony belongs (patient, formal caregiver, or informal caregiver) variables. Then, all 118 files were merged into a single .txt document, for a total of 81.752 *tokens* (that is, the smallest units, the words, into which the text is divided for analysis), thus composing a medium-sized corpus that was subsequently analyzed.

2.3.1. Emotional Text Mining Technique

Emotional Text Mining (ETM)^{48,49} was used for analyzing data. ETM is a semiotic approach, for unsupervised bottom-up analysis of unstructured corpora of different dimensions, to identify different levels of the narratives: content, social representations, and the symbolic-cultural matrix contained in the texts.^{48,49} ETM is a lexical profiling of social actors from their communications, situated within the socio-constructivist perspective, and has a psychodynamic orientation.⁵⁰ People's behaviors and actions are seen as an unconscious consequence of categorization and symbolization of reality.⁵¹ This then organizes the action and the production of language that then enables the shared social representation of reality, seen as a subjective product constructed based on the sociocultural representations of the environment within which the subject is embedded.^{52,53} ETM allows us to do a quantitative analysis of qualitative data, after a preliminary treatment of the corpus through the calculation, with a statistical process^{49,50} of lexicometric indices,⁵⁰ important to determine the methodological rigor, before data interpretation.

2.3.2. The operational phases

The data preprocessing analysis was carried out using T-Lab Plus 2022 Software version 7.2.1.4.^{46,47,54} The corpus was loaded into T-Lab to do different preliminary lexicometric analyses.^{46,47,54}

The first step is an automatic data processing phase for the calculation of some lexical indicators to assess whether it is possible to proceed: *token*, *Type/Token Ratio* (TTR), and *hapax* percentage (H%).^{55,56} Token is the total number of words contained within the corpus; TTR is the variety of different words contained in a corpus, also called lexical richness index; and hapax percentage is the number of unique words, that appear only once.^{46,47,54–59} Table 1 summarizes the indices of our medium-sized corpus, with a good lexical redundancy.

After that, text is fragmented into context units (i.e., parts of the text that are comparable to each other),^{46,54} with keyword selection and dictionary customizing, excluding stop-words, words belonging to the research question-stimulus^{48,49} – *Sclerosi* (Sclerosis), *Laterale* (Lateral), and *Amiotrofica* (Amyotrophic) –, and words belonging to the low and high ranks (Cordella et al., 2014; Giuliano & La Rocca, 2012b, 2012a; Greco, 2020) (see Table 1) – *SLA* (ALS), *malattia* (disease), *vita* (life), and *io* (I). The low rank was determined based on the sample size of the smallest group, whose value amounts to 10, so it was possible to have words also occur at least once in the smallest group. This methodological choice, which ensured that each term appeared at least once even in the smallest group, helped guarantee the reliability of the analysis and prevent any imbalance in the formation of thematic clusters. The high rank corresponds to the value of 226, calculated through a mathematical formula (Cordella et al., 2014; Giuliano & La Rocca, 2012b, 2012a; Greco, 2020). We obtained 746 definitive keywords belonging to the personalized dictionary. A thematic analysis of the elementary contexts (CE) was then conducted, through a bisecting *k*-means algorithm (which groups texts based on the similarity of the words used), with the following options: limitation to 20 partitions, and exclusion of all elementary contexts that do not have at least 2 co-occurrences. Limiting the analysis to 20 partitions allows obtaining a balance between the level of detail and the readability of the results. Excluding all elementary contexts that do not have at least 2 co-occurrences improves the reliability of the results by filtering out phrases that are too lexically light or isolated from the overall meaning of the text. This procedure

Table 1. Quantitative corpus indices and keyword selection criteria.

Quantitative corpus indices		Keyword selection criteria	
Texts	118	Upper frequency rank	226
Types	11.820	Lower frequency rank	10
Tokens	81.752	Keywords	746
Hapax	6454	CE in total	1987
TTR	0.145	CE in analysis	1920
Hapax %	54.6%	% CE in analysis	96.63%

allows for the identification of latent thematic structures within the text corpus, based on the co-occurrence and distribution of lexical units, by grouping elementary contexts into semantically homogeneous and interpretable clusters. The thematic analysis conducted is an automated, data-driven lexical-statistical analysis, carried out within a qualitative design using a mixed-methods approach. It is based on linguistic data and lexical clustering techniques, which make it possible to identify latent structures of meaning based on the distribution and co-occurrence of lexical units within the text corpus. The approach followed was that of ETM, with the aid of the T-Lab analysis software.^{46–48,54,57}

Then a match analysis on the lexical units*cluster matrix was made. This procedure allows us to explore the relationships between words and the identified thematic clusters and to identify the latent semantic dimensions that structure the corpus. The elements of the matrix are: the words in the rows, the clusters in the columns, and, in the cells, a number corresponding to the frequency of the words in the cluster. In this way, we obtain the distribution of words across the clusters.

The analysis is considered good if the corpus analyzed is more than 90% (Greco, 2016; Greco & Polli, 2020). We classified 96.63% (see Table 1) of elementary contexts of the corpus, and obtained an initial mapping of corpus content based on the co-occurrence of previously selected keywords.⁶⁰

The optimal partition comprised 5 clusters. Thus, 4 factors were identified to create a cultural space that imbues these clusters with meaning.⁵⁷ Clusters represent sets of semantically homogeneous elementary contexts (text segments) obtained through automatic classification algorithms based on the co-occurrence and distribution of lexical units. Each cluster thus identifies a latent theme in the corpus, that is, an area of meaning shared across multiple texts, characterized by specific words that tend to appear together. The factors (also called axes of communication) are the latent semantic dimensions that emerge from correspondence analysis and organize the symbolic space of the corpus. They represent polarities of meaning (e.g., high vs. low; individual vs. relational) along which both clusters and lexical units are distributed, allowing us to interpret how content is constructed and communicated, not just what is said. So, to simplify, cluster refers to thematic content and factor refers to the deep symbolic logic underlying the construction of discourse.

Semantic coding was carried out by three independent judges (the authors E.Z., A.G., and S.B.), who had been trained in advance on the classification criteria and were experts and confident with the analysis method used. After an initial phase of independent coding, the three judges compared their respective semantic attributions. Discrepancies and ambiguous cases were discussed until a unanimous consensus was reached.

The interpretation began with understanding the 4 axes of the factorial space, recognizing shared cultural dimensions and implicit categories, both positive and negative.⁵⁷ Next, the 5 clusters were placed in the factorial space through a cluster*factor matrix and similarly labeled by judges, referring to specific ALS categories⁵⁷ (see Table 2). On the term*cluster matrix, a correspondence analysis was done.⁶¹ Cluster*gender and cluster*group matrices were analyzed with chi-square and standardized residuals. This final step made it possible to identify differences in the distribution of clusters among men and women, as well as among the groups of patients, formal caregivers, and informal caregivers. This allows us to identify any significant associations between the emerging clusters and the participants' characteristics, highlighting which clusters are overrepresented or underrepresented in the various groups under consideration.

Table 2. Summary framework of textual analysis.

Clusters	%	Factors and the percentage of variance explained			
		Disease management	Assistance	Support	Effort
		34.25%	26.59%	21.39%	17.78%
Disease onset	12.29%		Relational 0.55		Personal 0.81
Difficulties	30.78%	Emotional -0.52		Self-direct 0.34	
Medical examinations	23.39%	Physical 0.76	Technological -0.28	Self-direct 0.22	
To cope	14.79%	Emotional -0.39	Technological -0.86	Social -0.53	Personal 0.34
Needs	18.75%		Relational 0.46	Social -0.58	Institutional -0.29

3. Results

Five main clusters and 4 main factorial communication axes emerge, which define the main issues that patients and caregivers refer to when they talk about ALS. The distribution of clusters in the factorial axes is shown in Table 2 and detailed further in the following sections.

3.1. The factors

Table 3 shows the factor summary with a top 20-word list sorted by absolute contribution for each factor.

3.1.1. Factor 1: Disease management

The first factor (34.25%) is Disease Management and concerns all those aspects that change from the onset of ALS onward, and which must be managed as best as possible. The two opposite poles regard emotional and physical disease management. Regarding emotional management of the disease, patients and caregivers often talked about the initial disbelief (e.g., “*Non riuscivo a credere che stesse succedendo proprio a me*”, “*I could not believe that this was happening to me*”) and the sense of discouragement that remains also in the next stages of the disease (e.g., “*Certo non sono mancati e non mancano i momenti di sconforto*”, “*Of course, there was and is no shortage of moments of discouragement*”). They also talk about a positive aspect concerning the willingness to rely on God and the strength to cope with everything that religion gave to them (e.g., “*Ricordo che da piccola mia nonna diceva: ‘È la mano di Dio che accarezza il tuo viso e benedice la tua giornata!’*”, “*I remember as a child my grandmother used to say, ‘It is the hand of God that caresses your face and blesses your day!’*”). Regarding physical management of the disease, emerge all the medical aspects of diagnosis and follow-up visits (e.g., “*Un susseguirsi di visite*”, “*A series of visits*”), the gradual loss of physical functions (e.g., “*Paralizzando gradualmente i muscoli corporei ma lasciando il cervello lucido*”, “*Gradually paralyzing the body muscles but leaving the brain lucid*”), and the need, especially in the terminal stages, to be cared for by a specialized, residential-type care center (e.g., “*Occorre, ripeto, assistenza infermieristica qualificata*”, “*There is a need, I repeat, for skilled nursing care.*”).

3.1.2. Factor 2: Assistance

The second factor (26.59%) is Assistance and 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. The two opposite poles regard technological and relational assistance. The technological pole concerns all the technical support needed because of the disease, from a diagnostic and medical care point of view. They talked about imaging techniques for assessing disease (e.g., “*mi prescrisse esami più approfonditi: un’elettromiografia e poi una nuova risonanza*”, “*prescribed more extensive tests: an electromyography and then a new MRI*”), and different life-support forms, like machines and/or computers (e.g., the visual eye communicator, the cough machine, assisted mechanical ventilation), which are configured as technological aids that enable patients to maintain social relationships. Concerning relational support, it is seen as an essential element in improving the psychological, emotional, and social QoL of patients and their families (e.g., “*noi non siamo mai stati lasciati soli; amici e parenti sono stati dalla nostra parte, insieme a noi*”, “*we were never left alone; friends and family were on our side, together with us*”), because it enables them to be able to live with ALS. This factor primarily concerns the methods of delivering care, cure, and patient management, and it exists along a continuum that contrasts a technological dimension, centered on devices and clinical interventions, with a relational dimension, based on direct interaction between the healthcare provider and the patient. It tries to answer the question “how is help provided?”.

3.1.3. Factor 3: Support

The third factor (21.39%) is Support, and concerns social and self-directed support. The social support stems mainly from the desire not to feel alone, to know other people with a story like one’s own, and to share stories of life and resilience (e.g., “*Questo inferno non può essere inutile, deve servire a qualcosa.*”; “*This hell can’t be useless, it has to serve a purpose...*”), but also to be part of associations, allowing ALS patients and their family members to create a community. (e.g., “*Creare una community, fare rete con chi vive la stessa esperienza, sentirsi meno soli.*”; “*Creating a community, networking with those going through the same experience, feeling less alone.*”). Concerning self-directed support, patients and caregivers talk about all those actions that they must do, independently, because of the increasing loss of physical abilities. For example, they talk about all the things that they must learn to do, both on emotional (e.g., “*ho dovuto imparare a confrontarmi con alcuni aspetti emozionali propri di questa malattia*”; “*I have had to learn to deal with some of the emotional aspects peculiar to this disease*”) and physical-technological side (e.g., “*[...] il computer [...] è un mio indispensabile compagno di viaggio che mi dà voce, facendomi esistere agli occhi del mondo con la dignità del mio pensiero.*”; “*[...] the computer [...] is my indispensable traveling companion giving me a voice, making me exist in the eyes of the world with the dignity of my thought.*”). Self-

Table 3. Factor summary with list of top 20 lexical units sorted by absolute contribution.

Factor 1: Disease management		Factor 2: Assistance	
Negative Pole: Emotional	Positive Pole: Physical	Negative Pole: Technological	Positive Pole: Relational
<i>lei</i> (She)	<i>diagnosi</i> (diagnosis)	<i>Pam</i> (Pam)	<i>aiuto</i> (help)
<i>occhio</i> (eye)	<i>medico</i> (physician)	<i>umano</i> (human)	<i>aiutare</i> (help)
<i>sentire</i> (feel)	<i>paziente</i> (patient)	<i>corpo</i> (body)	<i>sperare</i> (hope)
<i>forza</i> (strenght)	<i>mese</i> (month)	<i>te</i> (you)	<i>oggi</i> (today)
<i>amore</i> (love)	<i>visita</i> (visit)	<i>comunicazione</i> (communication)	<i>condividere</i> (share)
<i>scrivere</i> (write)	<i>sintomo</i> (symptom)	<i>Clop</i> (Clop)	<i>madre</i> (mother)
<i>guardare</i> (look)	<i>esame</i> (examination)	<i>fetente</i> (stinker)	<i>sorella</i> (sister)
<i>mano</i> (hand)	<i>assistenza</i> (assistance)	<i>tu</i> (you)	<i>padre</i> (father)
<i>grande</i> (great)	<i>neurologo</i> (neurologist)	<i>tecnica</i> (technique)	<i>assistere</i> (assist)
<i>vedere</i> (see)	<i>Centro</i> (Center)	<i>continuo</i> (continuous)	<i>marito</i> (husband)
<i>rimanere</i> (stay)	<i>cura</i> (care)	<i>preferire</i> (prefer)	<i>amico</i> (friend)
<i>piccolo</i> (small)	<i>ricovero</i> (hospitalization)	<i>tessuto</i> (fabric)	<i>famigliare</i> (familiar)
<i>Dio</i> (God)	<i>ospedale</i> (hospital)	<i>possibile</i> (possible)	<i>iniziativa</i> (initiative)
<i>mente</i> (mind)	<i>sanitario</i> (healthcare)	<i>immagini</i> (images)	<i>riuscire</i> (succeed)
<i>voce</i> (voice)	<i>primi</i> (first)	<i>consentire</i> (allow)	<i>fortuna</i> (luck)
<i>sorriso</i> (smile)	<i>neurologico</i> (neurological)	<i>nervo</i> (nerve)	<i>esperienza</i> (experience)
<i>ridere</i> (laugh)	<i>clinico</i> (clinical)	<i>evitare</i> (avoid)	<i>splendido</i> (wonderful)
<i>piacere</i> (pleasure)	<i>nuovo</i> (new)	<i>risultato</i> (result)	<i>mamma</i> (mum)
<i>bello</i> (nice)	<i>fornire</i> (provide)	<i>movimento</i> (movement)	<i>grave</i> (serious)
<i>viso</i> (face)	<i>peggiore</i> (worsen)	<i>computer</i> (computer)	<i>uscire</i> (get out)
absolute contribution from 1.32 to 0.32	absolute contribution from 3.62 to 0.50	absolute contribution from 3.25 to 0.53	absolute contribution from 0.71 to 0.25
Factor 3:Support		Factor 4: Effort	
Negative Pole: Social	Positive Pole: Self-direct	Negative Pole: Institutional	Positive Pole: Personal
<i>malato</i> (sick)	<i>giorno</i> (day)	<i>trovare</i> (find)	<i>anni</i> (years)
<i>famiglia</i> (family)	<i>gamba</i> (leg)	<i>grazie</i> (thank you)	<i>lavoro</i> (work)
<i>noi</i> (we)	<i>perdere</i> (lose)	<i>sofferenza</i> (suufering)	<i>chiamare</i> (call)
<i>AISLA</i> (AISLA)	<i>parole</i> (words)	<i>capire</i> (understand)	<i>fratello</i> (brother)
<i>persone</i> (people)	<i>momento</i> (moment)	<i>volontario</i> (volunteer)	<i>portare</i> (bring)
<i>persona</i> (person)	<i>usare</i> (use)	<i>prendere</i> (take)	<i>anno</i> (year)
<i>conoscere</i> (knoe)	<i>imparare</i> (learn)	<i>speranza</i> (hope)	<i>papà</i> (dad)
<i>campo</i> (field)	<i>braccio</i> (arm)	<i>bisogno</i> (need)	<i>cellula</i> (cell)
<i>associazione</i> (association)	<i>preparare</i> (prepare)	<i>garantire</i> (guarantee)	<i>diagnosticare</i> (diagnose)
<i>caro</i> (dear)	<i>passare</i> (pass)	<i>importante</i> (important)	<i>vivo</i> (alive)
<i>chiedere</i> (ask)	<i>cuore</i> (heart)	<i>voglia</i> (want)	<i>godere</i> (enjoy)
<i>coinvolgere</i> (involve)	<i>testa</i> (head)	<i>ricevere</i> (receive)	<i>età</i> (age)
<i>familiare</i> (familiar)	<i>ultimo</i> (last)	<i>cercare</i> (search)	<i>camminare</i> (walk)
<i>soluzione</i> (solution)	<i>letto</i> (bed)	<i>istituzione</i> (institution)	<i>lavorare</i> (work)
<i>vivere</i> (live)	<i>iniziare</i> (start)	<i>servizi</i> (services)	<i>convivere</i> (coexist)
<i>scegliere</i> (choose)	<i>Prova</i> (Try)	<i>presto</i> (soon)	<i>ultima</i> (last)
<i>Proprio</i> (Own)	<i>chiudere</i> (close)	<i>abbracciare</i> (embrace)	<i>mare</i> (sea)
<i>abbandonare</i> (abandon)	<i>muovere</i> (move)	<i>oculare</i> (ocular)	<i>crescere</i> (grow)
<i>ragione</i> (reason)	<i>destra</i> (right)	<i>nazionale</i> (national)	<i>trascorrere</i> (spend)
<i>posto</i> (place)	<i>muscolo</i> (muscle)	<i>lettera</i> (letter)	<i>utilizzare</i> (use)
absolute contribution from 5.64 to 0.44	absolute contribution from 0.82 to 0.29	absolute contribution from 0.68 to 0.16	absolute contribution from 23.07 to 0.44

directed support makes patients and their families feel that they are still alive, with a purpose in their lives, and with the knowledge that they can overcome the difficulties that the disease will bring. This factor primarily refers to the nature of the support, distinguishing between external social resources (family, support network) and self-directed resources, which are linked to individual coping and adaptation processes. It tries to answers the question “where does the support come from?”.

3.1.4. Factor 4: Effort

The fourth factor (17.78%) is Effort and concerns all the physical, emotional, and social actions to be put in place, from an institutional and personal side. Concerning institutional effort emerge all the aspects that researchers, associations, and all people in general should do to make ALS known and to raise general awareness of this disease (e.g., *“Costruire consapevolezza e comprensione della SLA”*; *“Building awareness and understanding of ALS”*). The effort is identified in researching to find new drugs or therapies, also to give greater hope to patients and their families (e.g., *“sperimentazione di nuovi farmaci, cosa che, in assenza di certezze, rappresenta una “salutare” fonte di Speranza”*; *“participating in the testing of new drugs, which, in the absence of certainty, is a “healthy” source of Hope”*). Concerning personal effort, a bit recalls that of self-directed support, which emerged in factor three. Patient and caregiver report how in the end they are the ones who must deal with ALS, and that therefore the main effort must come from themselves, like to move forward, not burdening the family too much (e.g., *“Questo mi fa fare i conti con sensi di colpa che non hanno ragione di essere, ma che esistono. E quindi, è una bella battaglia.”*; *“This makes me come to terms with guilt that has no reason to exist but does exist. And so, it is quite a battle.”*), and discovering all the little things that are beautiful despite ALS (e.g., *“vale la pena vivere quando si lotta per vedere la bellezza oltre il dolore”*; *“it is worth living when you struggle to see the beauty beyond the pain”*). Caregivers talked about the necessity to take charge of all those aspects patients can no longer take care of, especially in their daily actions (e.g., *“mi sono trovata anche a sollevarla di peso”*; *“I also found myself lifting her by weight”*), but also they reported the effort to find a balance between their work and personal life (e.g., *“obbligato ad abbandonare il posto di lavoro per poter assistere il proprio caro”*; *“forced to leave the workplace in order to care for their loved one”*). Caregivers reported that this effort is emotionally and physically exhausting (e.g., *“a volte il carico è maggiore di quello che una ragazza da sola può affrontare”*; *“sometimes the burden is greater than what a girl alone can handle”*).

3.2. The clusters

Five clusters emerge from the analysis, which refer to explicit specific ALS categories. The words within each cluster are shown in [Table 4](#). Each cluster is in a cultural space determined by one pole of the factors presented in the previous paragraph³⁸ (see [Table 2](#)). In the table in the [Appendix](#) section, the narrative extracts for each cluster are shown with the corresponding score.

3.2.1. Cluster 1: Disease onset

The first cluster (12.29%) is Disease Onset, and it is in the place of meaning related to the need to have relational assistance that supports what is the great personal effort put in (see [Table 2](#)). This cluster concerns everything that is related to the time when patients and their caregivers discovered the disease. Here are reported feelings of hopelessness and helplessness mainly related to physical abilities loss, social relationships diminishing, and consequences on work activities. At the beginning of the disease sadness and anger are the prevalent emotions. After that, fear emerges for the future and difficulty in accepting ALS consequences. After having accepted the new situation, some patients and caregivers speak about the new form of serenity they experience in social relationships, despite the illness, by being alive. This cluster, most of all, represents the writers' willingness to tell others about their experience, starting at the very beginning of their story.

3.2.2. Cluster 2: Difficulties

The second cluster (30.78%) is Difficulties, and it is in the place of meaning related to the emotional management of ALS, which consists mainly of support that patients or their caregivers gave to themselves (see [Table 2](#)). This cluster concerns all the difficulties that ALS patients and caregivers must face, in particular, the emotional ones. Patients said that they do not want to burden their caregivers too much, so they search for strategies to overcome the psycho-physical difficulties in their daily lives. Caregivers talk about their difficulty in accepting ALS, and in caring for their familiars. This causes in patients and caregivers a great deal of grief to deal with, a very important emotional difficulty related to the disease. Having strong social relationships and commemorating their loved ones' strength in fighting against ALS are strategies to surpass these difficulties.

3.2.3. Cluster 3: Medical examinations

The third cluster (23.39%) is Medical Examinations, and it is in the place of meaning related to the need to manage ALS on a physical level, through technological assistance and self-directed personal support (see [Table 2](#)). This cluster concerns all the medical examination aspects at the beginning of symptomatology and during its progression (e.g., fMRI, blood exams, and electromyography) to monitor ALS and intervene promptly with the necessary support. Concerning the initial stages of ALS, the struggle that patients and caregivers face and the fear of diagnosis emerge. The bodily aspect is predominantly narrated.

Table 4. Cluster summary with list of top 20 lexical units sorted by number of elementary contexts in the cluster (CE in CL).

Cluster 1: Disease onset		Cluster 2: Difficulties		Cluster 3: Medical examinations		Cluster 4: To cope		Cluster 5: Needs	
Words	CE in CL	Words	CE in CL	Words	CE in CL	Words	CE in CL	Words	CE in CL
<i>anni</i> (years)	151	<i>sentire</i> (feel)	104	<i>diagnosi</i> (diagnosis)	87	<i>corpo</i> (body)	35	<i>malato</i> (sick)	119
<i>lavoro</i> (work)	40	<i>giorno</i> (day)	89	<i>medico</i> (physician)	84	<i>Pam</i> (Pam)	30	<i>famiglia</i> (family)	73
<i>chiamare</i> (call)	30	<i>lei</i> (she)	76	<i>paziente</i> (patient)	77	<i>parlare</i> (talk)	29	<i>noi</i> (we)	65
<i>riuscire</i> (succeed)	29	<i>forza</i> (strenght)	67	<i>mese</i> (month)	66	<i>umano</i> (human)	26	<i>persone</i> (people)	61
<i>anno</i> (year)	24	<i>vedere</i> (see)	66	<i>prima</i> (first)	48	<i>tempo</i> (time)	26	<i>nostro</i> (our)	61
<i>portare</i> (bring)	23	<i>occhio</i> (eye)	66	<i>cura</i> (care)	47	<i>te</i> (you)	26	<i>trovare</i> (find)	54
<i>pensare</i> (think)	23	<i>momento</i> (moment)	62	<i>esame</i> (exam)	42	<i>tu</i> (you)	23	<i>vivere</i> (live)	47
<i>iniziare</i> (start)	20	<i>riuscire</i> (succeed)	58	<i>nuovo</i> (new)	41	<i>possibile</i> (possible)	20	<i>persona</i> (person)	37
<i>padre</i> (father)	17	<i>mano</i> (hand)	52	<i>visita</i> (visit)	38	<i>senso</i> (sense)	19	<i>conoscere</i> (know)	35
<i>camminare</i> (walk)	16	<i>amore</i> (love)	51	<i>sintomo</i> (synthome)	38	<i>cellula</i> (cell)	18	<i>aiutare</i> (help)	35
<i>papà</i> (dad)	15	<i>grande</i> (big)	49	<i>iniziare</i> (begin)	36	<i>Proprio</i> (Own)	17	<i>capire</i> (understand)	33
<i>madre</i> (mother)	15	<i>scrivere</i> (write)	47	<i>ospedale</i> (hospital)	34	<i>diverso</i> (different)	16	<i>chiedere</i> (ask)	32
<i>lavorare</i> (work)	15	<i>perdere</i> (lose)	45	<i>assistenza</i> (assistance)	33	<i>consentire</i> (allow)	16	<i>amico</i> (friend)	32
<i>storia</i> (story)	14	<i>mamma</i> (mum)	45	<i>arrivare</i> (arrive)	33	<i>utilizzare</i> (use)	14	<i>familiare</i> (familiar)	26
<i>esperienza</i> (experience)	14	<i>corpo</i> (body)	44	<i>passare</i> (pass)	30	<i>paura</i> (fear)	14	<i>cura</i> (care)	26
<i>oggi</i> (today)	13	<i>voce</i> (voice)	40	<i>neurologo</i> (neurologist)	30	<i>computer</i> (computer)	14	<i>Proprio</i> (Own)	24
<i>fratello</i> (brother)	13	<i>guardare</i> (look)	39	<i>Centro</i> (Center)	28	<i>giornata</i> (day)	13	<i>caro</i> (loved)	23
<i>sorella</i> (sister)	12	<i>rimanere</i> (remain)	38	<i>ricerca</i> (research)	27	<i>difficile</i> (difficult)	13	<i>bisogno</i> (need)	23
<i>vivo</i> (alive)	11	<i>dolore</i> (pain)	36	<i>primi</i> (first)	25	<i>morire</i> (die)	12	<i>aiuto</i> (help)	23
<i>permettere</i> (allow)	11	<i>diventare</i> (become)	35	<i>anno</i> (year)	25	<i>Continuo</i> (Continuous)	12	<i>AISLA</i> (AISLA)	23

3.2.4. Cluster 4: To cope

The fourth cluster (14.79%) is To Cope, and it is in the place of meaning related to emotional management, technological assistance, social support, and personal effort (see Table 2). Different coping strategies are reported to survive the disease, like technological aids (e.g., computers, eye communicators, and Non-Invasive Ventilation) that allow bodies to continue living and patients to continue having relationships, and the support of associations (e.g., AISLA) that combined with the enactment of personal determination (not give up) allow people to feel in a community and give a sense to their lives. Patients and caregivers also talk about the difficulties met in coping with ALS, and their fear when thinking about the future ALS implications. Formal caregivers report the need to cope with ALS through increasing investment in research, like testing of new drugs and therapies (e.g., stem cells).

3.2.5. Cluster 5: Needs

The fifth cluster (18.75%) is Needs, and it is in the place of meaning related to relational assistance, social support, and institutional effort (see Table 2). Patients and caregivers talk about all their needs starting from the diagnosis to the last stages of the disease, some of which are still perceived to be poorly seen and welcomed. The predominant needs are related to social,

medical, practical, and psychological assistance. The expressed desire is for a community effort to make patients visible, and ALS known, which in some situations unfortunately does not happen.

3.3. Group and gender cluster differences

Group and gender statistically significant differences emerge. Comparing the narrator of the testimony ($\chi^2 (8)=72.97$, $p<.001$) reveals differences in all clusters, except for the Disease Onset. Medical Examinations and To Cope clusters are more prevalent in patients' narratives than in those of informal caregivers' (both clusters) and formal caregivers' (only medical examinations) ones. The Needs cluster is more prevalent in formal and informal caregivers' narratives. Finally, the Difficulties cluster emerges more in informal caregivers' testimonies. Concerning gender ($\chi^2 (4)=19.87$, $p<.001$), the Medical Examinations cluster is more prevalent in women.

4. Discussion

This study aimed to understand the most significant positive and negative aspects of ALS across physical, clinical, psychological, relational, and emotional dimensions. ETM^{57,59} was employed to analyze the corpus of testimonies of various stakeholders involved in ALS, exploring the mental processes that influence communication, as well as individuals' attitudes, expectations, and behaviors.

A factorial cultural space with four axes emerges, which generally organizes individuals' ALS discourse. These axes comprise: Disease Management (physical vs. emotional), Care (technological vs. relational), Support (self-directed vs. social), and Effort (personal vs. institutional). Specific clusters include: Disease Onset, situated in the locus of meaning related to relational assistance and personal effort; Difficulties, primarily associated with the emotional management of ALS and self-directed support; Medical Examinations occurring both at the onset and throughout the disease course, situated within the locus of meaning related to physical management, technological assistance, and self-directed support; To Cope, located within the space of meaning constituted by ALS emotional management, technological assistance, social support, and personal effort; and Needs, associated with relational assistance, social support, and institutional effort. The analysis revealed a link between the "Needs" and "To Cope" clusters. The needs expressed (Needs) are linked to the coping strategies (To Cope) that patients and caregivers use to deal with ALS. This highlights the emotional and relational management that's key to dealing with ALS, care, and treatment. The results suggest that training programs could help formal and informal caregivers, along with interventions to enhance skills and strategies for coping, at the individual, family, and equipe levels. Approaches such as narrative therapies and interventions based on sharing experiences can promote awareness of lived experiences and rethinking life and care events. An important link also emerges between these aspects and the "Institutional Effort" axis' pole, highlighting the need to develop systemic and multidisciplinary interventions that support caregivers individually, organizationally, and socially.

These findings also align with existing literature, particularly regarding the themes most frequently reported by patients¹⁶⁻¹⁸ as well as by formal and informal caregivers.^{25,31-37} Notably, women discussed medical examinations more frequently, possibly due to their higher representation as informal^{62,63} and formal caregivers.⁶⁴ It would also be useful to examine in greater detail how male and female caregivers handle the bureaucratic and organizational aspects of scheduling medical appointments, in order to better understand the underlying dynamics and any significant differences, particularly in light of a potential gender-based distribution of the burden of clinical and care coordination. Patients spoke more about medical examinations, while narratives from formal and informal caregivers exhibited a greater emphasis on the theme of needs compared to those of patients; the theme of difficulties was more prominent in informal caregivers' testimonies.

4.1. Implications for clinical practice and future directions

Given these significant findings, future aims include performing discourse analysis⁶⁵ and positioning⁶⁶⁻⁶⁸ of testimonies. Investigating the evolution of patients' and caregivers' identities alongside their (re)narration of experiences^{69,70} may facilitate a more profound understanding of the elements related to ALS, its cultural symbolism, and the needs of all individuals involved. Only through such knowledge can suitable, individualized, person-centered psychological support programs – both individual and team-oriented – be developed to enhance the quality of life for patients, families, and healthcare professionals. These programs could be psychological support concerning coping strategies, emotions, and narrative therapies, and caregiver training groups to increase technical and emotional skills in managing ALS patients. This study is innovative, having identified factors and clusters of communication within a research field that remains in the nascent stages.

The findings from this study may guide the implementation of targeted intervention and support programs in line with the research-action paradigm of health psychology. This need arises in a context where the literature still indicates a limited availability of empirical evidence for both patients and informal caregivers.^{71,72} These results illustrate how various factors can influence an individual's QoL, whether they are a patient or a caregiver. Increasing the number of testimonies of formal caregivers could yield additional insights into potentially significant aspects that have not been accentuated here. Considering these results, it would be appropriate to pursue further studies, such as conducting interviews and/or focus groups with patients (particularly recommended during the early or intermediate stages of the disease when communication remains feasible), as well as informal and formal caregivers, to meticulously understand their experiences and analyze them within the socio-cultural contexts in which they occur. It would also be interesting to conduct emotional text mining analysis in other countries and/or cultures, to explore any differences in the factors of communication and issues perceived as most important when talking about ALS. In particular, comparative studies using ETM would help clarify whether the contrast between "Technological" and "Relational" Care is a universal feature of the ALS experience or is a specific element in the Italian context.

4.2. Limitations

This study has some limitations. The narratives may have been posted online by people who have benefited from them, and patients and caregivers who approach the disease differently or did not have the chance to express themselves online may not have been included. The testimonials included in the study cannot be clinically verified; consequently, it is not possible to determine with certainty whether the individuals who provided the testimonials are actually people diagnosed with ALS or caregivers of patients with the disease. Furthermore, no information is available regarding clinical variables such as functional status (e.g., ALSFRS-R score) or disease duration. However, the nature of the sources used—which prioritize spontaneous narratives rather than those mediated by structured clinical contexts—allows for access to ecological accounts of lived experience. Finally, this study cannot be considered representative of all those with ALS and their caregivers. Further studies with more participants are needed.

5. Conclusion

The results obtained not only describe the cultural-symbolic matrix associated with ALS but also allow for reflection on its clinical implications. Identifying the main clusters can be a useful tool for guiding palliative care interventions, contributing to a more personalized approach to psychological and care support, and facilitating assessment processes that are more attuned to the symbolic dimensions of the ALS experience. Understanding the emotional and representational dimensions expressed in the various clusters can facilitate the development of targeted interventions for patients and caregivers. These interventions can promote approaches that are responsive to emerging needs and adaptation processes to the disease. Healthcare professionals caring for patients with ALS can use these thematic configurations as an interpretive framework to recognize patients' and their informal caregivers' physical, emotional, and relational needs earlier, moving beyond a purely symptomatic assessment. This shifts from an objective, clinical assessment of the disease to an assessment of how patients and caregivers experience it, which translates into genuine care through active, empathetic listening and personalized therapeutic pathways. Regarding informal caregivers, this study highlights important elements to include in personalized support programs, such as support groups, psychological supervision, and narrative spaces (e.g., writing or sharing experiences). Furthermore, the results of this study allow for the structuring of interventions tailored to patients' positions within their diseases. Understanding these discursive configurations can facilitate more attuned communication between patients and professionals, patients and family members, and family members and professionals. This reduces misunderstandings and fosters a stronger therapeutic alliance. In the advanced stages of ALS, these findings can inform interventions that address existential needs, acceptance of physical decline and inevitable death, and other issues that arise as the disease progresses. These interventions promote person-centered care aimed at improving quality of life despite the awareness of impending death. In conclusion, mapping the cultural-symbolic matrix of ALS within the context of palliative care can facilitate interventions that are more sensitive to the meanings attributed to the experience of ALS. This improves clinical communication and the psychological well-being of everyone involved.

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Ethical considerations

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 establishes that only researches involving individuals and/or with significant ethical implications are 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 (CET) of the Lombardy Region (Articles 3 and 4), which identifies the competences of the CET 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, also making written testimonies posted online anonymous.

Consent to participate

Since no participants were recruited, informed consent was not necessary.

Consent for publication

This is a study that does not directly involve people but analyzes testimonies spontaneously produced and already voluntarily posted online, accessible to anyone with an Internet connection. Since no participants were recruited and all the testimonies were already posted online, consent to publish was not necessary.

Author contributions

All authors contributed to the conception and design. Material preparation, data collection, and analysis were performed by Elisa Zambetti, supervised by Simone Belli and Andrea Greco. The first draft of the manuscript was written by Elisa Zambetti, and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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The materials are available upon request from the corresponding author.

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Appendix

Appendix. Narrative extracts, related to their cluster membership, with the corresponding score

Cluster	Context
Disease Onset	"L'ipotesi della SLA non mi era mai passata per la testa come causa del mio infortunio alla spalla. Sono uscita dallo studio del neurologo, mi sono seduta e ho pianto. Tutti conoscono la temuta prognosi di 2-5 anni. Continuavo a ripeterla nella mia mente. 2-5 anni mi porteranno a vedere mia figlia compiere 9 anni al massimo. Con 2-5 anni non arrivo nemmeno a 45 anni." (score: 1295.0307) ("The ALS hypothesis had never crossed my mind as the cause of my shoulder injury. I walked out of the neurologist's office, sat down and cried. Everyone knows the dreaded prognosis of 2-5 years. I kept repeating it in my mind. 2-5 years will take me to see my daughter turn 9 years old at most. With 2-5 years I won't even make it to 45.") "Accadeva dopo sei anni dal primo intervento e questo professore mi disse che era una malattia che non si conosceva a fondo e i quali sintomi potevano essere confusi con altre cause. Mi dissero che aveva ancora pochi anni di vita e con una qualità di vita non augurabile. Mia madre si è spenta nel 1994 a soli 56 anni di vita. Le conseguenze in me sono state 9 anni di sofferenza." (score: 684.5031) ("It happened six years after the first surgery, and this professor told me that it was a disease that was not known a fact and whose symptoms could be confused with other causes. I was told that she still had a few years to live and with an undesirable quality of life. My mother passed away in 1994 at only 56 years of age. The consequences in me have been 9 years of suffering.") "Mi chiamo Monique. Ho 40 anni (quasi 41) e sono una mamma single. Mi è stata diagnosticata la SLA a 32 anni. Ero infermiera professionista, ma, nel 2017, ho dovuto lasciare il mio lavoro... Perdere la mia indipendenza e la capacità di lavorare sono state le perdite più dure." (score: 609.6267) ("My name is Monique. I am 40 years old (almost 41) and a single mom. I was diagnosed with ALS when I was 32 years old. I used to be a registered nurse, but, in 2017, I had to quit my job... Losing my independence and ability to work have been the hardest losses.")

(continued)

Appendix. (continued)

Cluster	Context
Difficulties	<i>“Il prossimo scoglio da affrontare sarà quando non le funzioneranno più gli occhi. Dovrebbe essere preparata, non ne vorrebbe parlare e la capisco, ma io ci penso, si parla di un momento disastroso, ma bisogna esser preparati anche a questo. Cosa posso fare io, se lei non riuscirà più a scrivere e comunicare, come potrò aiutarla? La sua malattia ci ha unite.”</i> (score: 109.5081) (“The next obstacle to face will be when her eyes no longer work. She should be prepared, she wouldn’t want to talk about it, and I understand her, but I think about it, you talk about a disastrous time, but you have to be prepared for that too. What can I do, if she can no longer write and communicate, how can I help her? Her illness has brought us together.”) <i>“Ho visto mia nonna soffrire, l’ho vista affrontare una cosa più grande di lei e da sola, l’ho vista farsi togliere da questa malattia la possibilità di godersi a pieno la vita... ed è grazie a lei che oggi sono quella che sono, pronta ad aiutare tante altre vite che vengono colpite da questo grande male”</i> (score: 108.0789) (“I’ve seen my grandmother suffer, I’ve seen her face something bigger than herself and alone, I’ve seen her have this disease take away her chance to fully enjoy life... and it’s thanks to her that I am who I am today, ready to help so many other lives that are affected by this great evil”) <i>“È pesante, perché a volte la notte non riesce a riposare benissimo per i dolori, ma non disturba nessuno né ci chiama. È in quel letto sì, ma è molto attenta. Ci ricorda cosa dobbiamo fare, le bollette da pagare, la spesa. È sempre presente, la malattia ogni giorno le mangia un po’ di forza, ma lei resiste non molla e questo ci aiuta ad andare avanti, ogni giorno.”</i> (score: 79.9163) (“It is heavy, because a times at night she cannot rest very well because of pains, but she does not disturb anyone or call us. She is in that bed yes, but she is very attentive. She reminds us what we have to do, the bills to pay, the groceries. She is always there, the illness every day eats away some of her strength, but she resists not giving up and that helps us to go forward, every day.”)
Medical Examinations	<i>“Il Medico di medicina generale (MMG) formula il sospetto diagnostico ed invia il malato dal neurologo. Quest’ultimo successivamente invia il paziente in un centro di riferimento per la SLA. Il neurologo del centro di riferimento formula una diagnosi accurata, all’incirca entro dieci mesi dall’esordio dei sintomi.”</i> (score: 422.4938) (“The medical general practitioner formulates diagnostic suspicion and sends the patient to the neurologist. The latter subsequently sends the patient to an ALS referral center. The neurologist at the referral center makes an accurate diagnosis, approximately within ten months after the onset of symptoms.”) <i>“Io sono un’infermiera. Per tanti anni sono stata una caposala dell’ospedale di Macerata e Stefano era un medico Otorino ed in quanto medico alla comparsa dei primi sintomi (non riusciva ad allacciarsi il polsino della camicia del braccio sinistro) ha pensato alla SLA e il neurologo dott. Logullo in breve tempo ha confermato la diagnosi.”</i> (score: 277.4153) (“I am a nurse. For many years I was a head nurse at Macerata Hospital and Stefano was an ENT doctor and as a doctor at the appearance of the first symptoms (he could not tie the cuff of the shirt on his left arm) he thought ALS and neurologist Dr. Logullo in short time confirmed the diagnosis.”) <i>“Non riuscivo a credere che stesse succedendo proprio a me. Poi sono arrivate le visite con altri neurologi, risonanze magnetiche, test genetici, e molti altri esami per escludere altre diagnosi - ma la conclusione è stata sempre la stessa: SLA. Il primo mese post-diagnosi è stato un mese di panico.”</i> (score: 247.6992) (“I could not believe that this was happening to me. Then came visits with other neurologists, MRIs, genetic tests, and many other tests to rule out other diagnoses-but the conclusion was still the same: ALS. The first-month post-diagnosis was a month of panic.”)

(continued)

Appendix. (continued)

Cluster	Context
To Cope	<i>“Pam, Clop... cloffete, cloppete, clocchete...Pam! Gli altri, gli incontri, il nuovo punto_di_vista. Persone che hanno intrapreso una lotta tenace, che non mollano, guerreggiano contro tutte le Fetenti mandate in terra da un angelo cinico. Fino ieri non le vedevi, quelle persone, o almeno, le avevi viste ma non osservate. Adesso per te è tutto più chiaro.”</i> (score: 190.3271) <i>“Pam, Clop...cloffete, cloppete, clocchete...Pam! The others, the meetings, the new point_of_view. People who have waged a tenacious struggle, who do not give up, war against all the Stinkers sent to earth by a cynical angel. Until yesterday you did not see them, those people, or at least, you had seen them but not observed them. Now everything is clearer for you.”</i> <i>“Dal momento_in_cui abbiamo ottenuto l’autorizzazione, Marzo 2011, abbiamo iniziato a procedere con la sperimentazione attraverso il trapianto di cellule staminali in pazienti affetti da SLA. Le cellule utilizzate sono di tipo staminali cerebrali umane, derivate da feti d’aborto spontaneo, con una tecnica analoga a quella della donazione d’organo”</i> (score: 63.7704) <i>“Since_the_time_in_which_we_obtained_permission_in March 2011, we have been proceeding with experimentation through stem cell transplantation in ALS patients. The cells used are human brain stem type, derived from miscarriage fetuses, using a technique similar to organ donation”</i> <i>“Certo Paolo, non_so ancora come, ma lo farò. Te lo prometto! Ma ti prego, promettimi che anche tu cercherai di essere più_forte. Non mi aiuti piangendo e non posso spendere tutte le mie energie confortandoti premurosamente. Devo pensare a me, a te e ai nostri bimbi ed è già dura. Farvi male mi fa male, ma non voglio un altro motivo per cui essere preoccupata o arrabbiata”</i> (score: 34.7824) <i>“Of course Paul, I don’t know how yet, but I will. I promise you! But please promise me that you will also try to be more_strong. You don’t help me by crying and I can’t spend all my energy caringly comforting you. I have to think about me, you and our babies and it is already hard. Hurting you hurts me, but I don’t want another reason to be worried or angry”</i>
Needs	<i>“È importante garantire al malato il necessario perché lui e la sua famiglia possano condurre una vita dignitosa e serena. Bisognerebbe contribuire ad allontanare dalla persona malata le insicurezze e le preoccupazioni che attanagliano il malato e tutta la famiglia.”</i> (score: 380.0055) <i>“It is important to ensure that the sick person has what is necessary for him and his family to lead a dignified and peaceful life. It should help to remove from the sick person the insecurities and worries that grip the sick person and the whole family.”</i> <i>“La nostra malattia può abbandonare la zona buia per farsi luce e noi possiamo essere utili ad altri compagni di avventura che non hanno le nostre stesse possibilità di farsi valere. La nostra vita diventa preziosa proprio nella relazione con gli altri malati. Questo è lo spirito di un’associazione come AISLA: persone che aiutano persone.”</i> (score: 372.12) <i>“Our illness can leave the dark zone to become light, and we can be of use to other fellow adventurers who do not have the same opportunities as we do. Our lives become valuable precisely in relationships with other sick people. This is the spirit of an association like AISLA: people helping people.”</i> <i>“Ho avuto l’occasione di conoscere tanti, troppi malati di SLA e di constatare come ci siano delle grosse differenze di trattamento tra malati: addirittura nella stessa regione. Quanti malati che hanno accettato la tracheostomia si sono pentiti perché, invece di avere un percorso di vita difficile ma dignitoso, si sono trovati a combattere per avere i più elementari dei diritti.”</i> (score: 255.7725) <i>“I have had the opportunity to meet many, too many ALS patients and to see how there are big differences in treatment between patients: even in the same region. How many sufferers who accepted tracheostomy regretted it because instead of having a difficult but dignified life path, they found themselves fighting for the most basic of rights.”</i>

Glossary

AISLA	Italian Association of Amyotrophic Lateral Sclerosis
ALS	Amyotrophic Lateral Sclerosis
CE	Elementary Context
ETM	Emotional Text Mining
fMRI	functional Magnetic Resonance Imaging
H%	Hapax percentage
QoL	Quality of Life
TTR	Type/Token Ratio