ECRONICON OPEN ACCESS

EC PSYCHOLOGY AND PSYCHIATRY
Thematic

Psychological Support on Individuals with Amyotrophic Lateral Sclerosis (ALS)

Nikolaos Panagiotopoulos*

Msc in Clinical Psychology, Università di Roma La Sapienza, Greece

***Corresponding Author:** Nikolaos Panagiotopoulos, Msc in Clinical Psychology, Università di Roma La Sapienza, Greece.

Received: September 28, 2019; **Published:** November 27, 2019

Abstract

"Psychological support aims at life itself" in order to make sense of it so that it is worth living.

Such a statement could be defined as the "basic principle" of any kind of psychological intervention in general and in particular of interventions related to degenerative diseases. Starting from an intervention aimed at preserving human health and dignity requires some clarification on the basic concepts that will help to identify the choices and best strategies/practices.

One of the goals of such support will therefore be to manage the emotional aspects that accompany the patient from the time of diagnosis and throughout the course of the disease. The therapeutic challenge is to establish a "multidimensional" healing process that involves not only the sick but also the family (or the support available). As we shall see, good practices in particular should address, inter alia, the moments of sadness, anger, ambivalence and anxiety that naturally accompany people who care for patients at all stages of the disease and aim, if managed well, to used as elements of transformation and change within and within the family without becoming explosive and disastrous.

Keywords: *Psychological Support; Amyotrophic Lateral Sclerosis (ALS)*

Introduction

Like health, illness was also a concept that has often been used in the past in a way that disoriented both intervention policies and strategies. The World Health Organization (WHO), defines health as a state of physical and mental well-being and considers not only an individual factor but also a collective factor that takes into account not only the component of physical homeostasis but also the psychological and social components. This new concept of health automatically changed the traditional definition, which regarded health simply as "no symptoms". On the same line, 'psychology has contributed to the proposition of a broad vision of 'defect', including its biological and social consciousness, which provides a picture of the individual as a whole, in the complex interplay between integrated and defective components, in the psychological dynamics that characterize certain situations and some circumstances (Zanobini, Usai 1998). A person with an illness such as ALS is primarily a person who possesses among the innumerable components of personality the particularities of his body that may have more or less significant negative consequences, depending strictly on the socio-environmental, economic, cultural and family life in which he lives. The fact is that a person's degree of disadvantage is not only related to the extent of the physical or mental injury: it is largely a social phenomenon.

ALS as a degenerative nervous disorder requires a continuous and repeated adjustment effort that involves activating actions that will help him to create a new psycho-physiological balance that will be restored by the ongoing psychological support of people with ALS and their immediate environment. In this context, psychology aims to promote psychological adjustment with the aim of ensuring mental integrity and, as far as possible, accompanying the patient throughout the course of life and helping him to deal with modifiable disorders as well as integrate them irreversible.

The patient's emotional state consists of a series of cognitive, emotional, and behavioral reactions that affect the development of the disease and the mental health of the people close to it. At each stage of the disease, in fact, a person's psychological reactions are the result a complex integration between the memory of experiences, the perception of future threats and the resources available. Anxiety, anger, and depression are indicators of the patient's physiological response to the disease.

When these levels are high or with chronic manifestations and are associated with intense subjective discomfort, psychosocial functioning and interpersonal relationships, we are rather talking about a pathological reaction. Immediately after the diagnosis of ALS, there is a mental discomfort with a prevalence of the depressive spectrum. In advanced diseases, psychiatric symptoms, personality disorders or even organ-based mental disorders can occur. Consequently, the provision of psychological support reflects more aspects of human behavior and begins with communication in various contexts and domains. Communicate with family members with the patient and especially (when available) with children or adolescents. Therefore, within a family unit, it will be important to reflect on the ways in which communication will be used to explain the situation and inform people without scaring anyone and without creating further uncertainty.

A person with an illness such as ALS is primarily a person who possesses between the innumerable components of personality and body, peculiarities that may have more or less significant adverse consequences, depending heavily on socio-environmental, economic, cultural, and family life in which she lives. The extent of a person's problem is not only related to the extent of the physical or mental injury: it is largely a social phenomenon.

The patient's emotional state consists of a series of cognitive, emotional, and behavioral reactions that affect the course of the disease and the mental health of the people close to it.

In each phase of the disease, in fact, a person's psychological reactions are the result of a complex integration between the memory of experiences, the perception of future threats and the resources available. Anxiety, anger, and depression are indicators of the patient's physiological response to the disease. But when these levels are high or with chronic manifestations and are associated with intense subjective distress, dysfunctional psychosocial reactions and interpersonal relationships, then we are rather talking about a pathological condition.

Addressing emerging traumatic and mourning aspects of the disease means creating a therapeutic process that takes care of the available family resources and guarantees the integrity of the family unit. Assisting in enabling good practice involves preserving the social and relevant part of functions, processing reaction and integrating physical and psychological changes, exchanging information and activating protocols that guarantee so-called "quality and right to life". "In particular, the right of access to health resources must be guaranteed in order to exploit the 'best practices' which must be revised in line with the new protocols.

The right to health has been recognized internationally by the Universal Declaration of Human Rights, adopted by the United Nations General Assembly on 10 December 1948 and the World Health Organization (WHO) Constitution. To this end, the WHO has confirmed that health protection is achieved not only through the treatment of illnesses and diseases, but also by favorable conditions of prosperity through the elimination of factors that adversely affect collective health. This principle was further reinforced by the Alma Ata Declaration (Alma Ata Declaration of Primary Care), adopted at the International Conference on Primary Health Care held from 6 - 12 September 1978 in Alma Ata, Soviet Union and was confirmed in the Ottawa Charter during the 1986 International Conference on Health Promotion.

Therefore, promoting health and well-being entails a systematic assessment of the environmental impact of disease on human well-being and the adoption of coordinated public policies in areas other than health. As we shall see, however, despite official statements, all these rights remain in many cases a utopia for many patients with ALS who today continue to struggle on their own, not for lack of information, but because of the lack of a system capable of promoting them.

But today we know that in cases of disabilities such as ALS, it is important for families to benefit from valid support in many ways (psychological, medical, practical, etc.) and to remember that 'difficult' does not necessarily mean impossible.

On the difficult road of the ALS, the words of W. Bion today, remain words of inspiration to all those struggling with the disease..... "Dispose of your memory, reject the future time of your desire: forget both so that leave room for a new idea".

EFNS guidelines on clinical management of ALS (MALS)

Multidisciplinary care and recommendations

Although multidisciplinary care is not limited to special care, the term "interdisciplinary" in ALS has become synonymous with the care provided in various areas of specialized ALS care clinics and has been shown to provide high quality care. It is a system of specialized services that includes the effective provision of interdisciplinary care that requires collaboration, coordination and seamless transition between numerous healthcare professionals within and between industries, through a range of health and industry services. The guidelines for clinical management of ALS have been published in Europe, the United Kingdom and the United States. However, patient compliance with health professionals' recommendations may vary. Ideally, patients should be reviewed every 2 - 3 months with the multidisciplinary team (MDC) who maintains regular contact with the patient and family between visits. Patients must be followed by the same neurologist who, in turn, should work closely with the patient's attending physician. It is important that coordination of patient care requires effective communication between the MDC team, the palliative care group and community-based services. The standards in ALS care have been defined by clinics specializing in ALS. patient care based on the predefined criteria has improved the quality of life of patients and increased the availability of aids and equipment.

MDC (Studies and results)

Trend., *et al*. found an improved 7.5-month survival while 1-year mortality decreased by 30% for patients who attended a national ALS clinic in Ireland. Extensive survival rates have also been found in a more recent Irish study focusing on the effects of an MDC ALS on patient survival. 32 the cited studies report better results than non-interdisciplinary care. Although, since comparisons do not always fit well, the generalized comparison is difficult. Zoccolella., *et al.* found that MDC Care did not improve survival compared to general neurological care. However, respiratory and dietary interventions were low for these groups and MDC is not directly linked to community-based services or palliative care services. Survival in ALS is likely to be influenced by the complex decision-making processes taking place in the multidisciplinary environment and not by the impact of symptomatic interventions alone. Comparisons between clinical cohorts and population-based cohorts of patients have confirmed a reference bias: patients who attend multidisciplinary clinics tend to be younger and have symptoms longer than those who do not.

In another study, patients attending multidisciplinary clinics have fewer hospital admissions and shorter hospital stays than those attending general clinics. The increase in the use of riluzole ventilation and attention to nutrition in relation to the previous reference to palliative care services is likely to contribute to the increased survival of those attending multidisciplinary clinics, increasing the quality of life of patients with ALS (perhaps in relation to a greater vision of appropriate aids and devices).

Interdisciplinary assistance models in SLA

As we have seen previously, a coordinated and inter-professional approach to addressing the needs of ALS patients is represented in various care models. These models share a patient-centered approach and recognize that patients and their families are important stakeholders in care and have active roles in decision-making. Family care givers are critical to the care and support of people with ALS, and they also address multiple losses in their role. Caring for a person with ALS can be physically and emotionally demanding for family members and family care givers who feel they are supported by health professionals.

Although family care providers tend to play a key role in assisting the patient, the needs of family carers should not be neglected by service providers. As with patients, caring for caregivers in the face of ALS challenges takes on high levels of responsibility within the society. The multidisciplinary care of ALS is dynamic and should have the ability to adapt to different healthcare environments. The multidisciplinary care of ALS can therefore be provided by public or private institutions that provide neurology, rehabilitation and palliative care services in the primary, secondary and tertiary sectors. In many cases, patients and families work with doctors from various interdisciplinary groups who form their broader specialized multidisciplinary service - a team within a team. ALS care is more effective if coordinated between specialized MDCs, palliative care groups (including primary care) and community care. Corr., *et al.* 18 demonstrated that the close link between a clinic specializing in ALS, community-based services (e.g. allied health workers, doctors and office services) and the voluntary sector (i.e. the local ALS association) can provide effective care in patients with ALS. Furthermore, there are potential benefits from nursing coordinators specializing in a liaison role, particularly in the later stages of the disease.

The multidisciplinary care ALS is suitable throughout the course of the disease (i.e. diagnostics, in recovery development and terminal phase). "Recovery" is understood in the context of interventions that can help patients and their families adapt to the physical and psychological challenges of living with ALS (i.e. counseling, social support, spasticity relief, provision and training in assistive technologies) instead of recovering physical loss or treating cognitive change encountered by patients with ALS. The term "palliative" instead is based on an approach that seeks to alleviate the physical, psychological and existential difficulty.

Communication strategies

As we have already seen, the introduction of an ALS diagnosis requires skill. If not performed properly, the effect can be devastating, leaving the patient with a sense of abandonment and destroying the doctor-patient relationship.

More than half of the patients interviewed and caregivers say they are not satisfied with the way the diagnosis was communicated.

Studies of other deadly diseases demonstrate advantages in the use of specific techniques. Patients/caregivers are more satisfied if effective communication strategies are used and more time is spent discussing the diagnosis. The callous delivery of the diagnosis can affect the psychological adjustment of the mourning/assisting mourners later.

Recommendations

- The diagnosis should be pursued as soon as possible. Patients suspected of having ALS should be given high priority to an experienced neurologist.
- All new suspected cases should undergo detailed clinical and paraclinical examinations.
- In some cases, further investigation may be necessary.
- Repeat investigations may be required if the initial tests are equivocal.
- The revision of the diagnosis is advisable if there is no evidence of typical progression or if the patient develops atypical characteristics.
- The diagnosis must be communicated by a consultant with a good knowledge of the patient.

- The doctor should start the consultation by asking what the patient already knows or suspects.
- The diagnosis should be made in person, ensuring sufficient time for discussion (suggest at least 45 - 60 minutes). Provide printed material on the disease, support and defense organizations and informational websites. A copy of the letter summarizing the discussion can be useful for patients and assistants.
- Assure patients that they will not be abandoned by health services and that they will be supported by an ALS professional assistance team (where available), with periodic checkups by a neurologist. Organize a first follow-up visit, ideally within 2 - 4 weeks.
- Avoid the following: withhold the diagnosis, provide insufficient information, impose unwanted information, provide insensitive information, remove or not provide hope. Treatment should be started as soon as possible after diagnosis. Realistic expectations for therapeutic effects and potential side effects should be discussed with the patient and caregivers.

Assisted communication

ALS causes progressive loss of independence and an increased need for help with activities of daily living. Carers progressively increase the time devoted to care. in interactions between the patient and the doctor, from the time of diagnosis to the The burden of caregivers concerns personal and social restrictions and psychological and emotional problems. Caregivers frequently look for information on ALS and many actively participate in decision-making process related to advance directives and end-of-life care. Some symptoms of ALS cause particular tension in carers. If the patient loses effective communication, carers can become intellectually and emotionally isolated. The use of augmentative alternative communication devices can help restore communication. Several studies have shown that the provision of mechanical ventilation for patients' causes.

A special effort for caregivers, reducing their quality of life and increasing their responsibilities related to ventilator management and foreseeing the rising costs of care. Sexuality can be a problematic problem for many ALS patient-caregiver couples. Reported problems include decreased libido, partner passivity and the caregiver's own passivity. The most frequent reasons cited were physical weakness and body image changes due to ALS. Half of ALS patients in a UK and German cohort died at home. The anticipation of patients' imminent deaths may increase the caregiver's discomfort and anxiety. However, Neudert., *et al*. reports that most ALS patients die peacefully and no patient suffocates death if good palliative care measures are in place.

Some health workers go through a grieving process from the moment the diagnosis is given. The anticipation of future loss is as important as the loss itself in bringing about psychological difficulties. The caregivers risk feelings of exhaustion, repercussions due to forced changes in living conditions and financial difficulties.

Recommendations

- Caregivers should be recognized in their dual role in the disease process: they are the most important resource for the patient, yet they are themselves and their needs as caregivers must be addressed.
- Ideally, caregivers should be involved from the time of diagnosis, while preserving patient autonomy.
- Your health needs must be taken into consideration. Physical, psychological and spiritual support should be provided when necessary.
- Maintaining communication between patients and healthcare professionals is important.
- The likelihood of a peaceful death process should be communicated to patients and their caregivers/relatives.
- Mourning counseling and support should be stamped on all caregivers.
- The use of the various devices and of any electronic crew should be taught to patients and caregivers.

Recommendations

- The patient and caregiver should be taught the technique of assisting expiratory movements using an assisted manual cough (can also be performed by a physiotherapist).
- The use of a mechanical protection device may be useful, particularly in the context of an acute respiratory infection.
- A portable home suction device and an ambient humidifier may be useful.

Cognitive disorders in patients with amyotrophic lateral sclerosis.

Depressive symptoms and pharmacology

ALS is a disease that affects the cognitive system, despite the classic view that cognitive functions remain intact. Unfortunately, it is not yet clear what mechanisms cause dementia and what mild cognitive impairment in patients with ALS. A better understanding of these disorders and their birth mechanisms will lead to improved patient care of their mood changes. It will also improve their quality of life and provide valuable information on the pathogenesis of neurodegeneration.

Recommendations

- Treat ALS depression with an appropriate antidepressant, such as amitriptyline, an SSRI or mirtazapine. The SSRI can preferably be in elderly patients or those with cognitive disabilities (GCPP).
- Treat anxiety with bupropion or benzodiazepines such as diazepam tablets or suppositories, Temesta 0.5 mg tablets two or three times a day or sublingual lorazepam.
- Inform the patient and relatives that emotional lability is not a sign of an additional mood disorder, but is due to the effects of ALS on the brain.

Insomnia and fatigue problems

Insomnia is common in the last months of life in patients with ALS. There are probably many causes, including depression, cramps, pain and respiratory distress, which should be treated if identified. For insomnia in ALS, amitriptyline and zolpidem are the most commonly used drugs. Fatigue is a frequent and potentially debilitating symptom. It can be of central and/or peripheral origin. An open-label study and a small Class I study with modafinil revealed a significant reduction in fatigue with a number of patients to be treated. However, long-term effects in ALS have not yet been studied.

Recommendations

- Treat insomnia with amitriptyline, mirtazapine or appropriate hypnotics (e.g. Zolpidem).
- Due to debilitating fatigue, modafinil (level A) can be considered.

Language deficit and communication in patients with ALS

Most of the clinically apparent communicative difficulties in ALS result from dysarthria. However, subtle changes in language function may also occur, as evidenced by reduced verbal production, reduced spelling ability, increased word search difficulties and impaired auditory comprehension of specific language classes (for example verbs more than names) and more complex internal language constructs. Deficits can be subtle and identifiable only with formal neuropsychological tests. Language impairment can reduce the quality of life of both patients and caregivers and can make clinical management difficult. Formal neuro-psychological assessment and support may be required in patients with linguistic deficits in concomitant evolution. The general objective should be to optimize the effectiveness of communication, focusing on meaningful interpersonal communication with the carer and family. This should include strategies for effective conversations and the introduction of alternative communication devices where appropriate.

Augmentative and alternative communication systems can substantially improve the quality of life for both patients and carers. Prosthetic treatments (palatal lifting and/or palatal augmentation prosthesis) may be useful in reducing hyper-jointness and improving joint, but there are no formal comparative studies on ALS. For those who require complete mechanical ventilation, high-tech augmentative, eye-gaze or head-tracking communication devices may be useful.

Recommendations

- A regular assessment (i.e. every 3 - 6 months) of the speech and language function by a language and language expert therapist is recommended.
- Those with evidence of early language deficiency should undergo complete neuropsychological testing.
- The use of appropriate communication support systems (ranging from pointing cards with figures or words to computerized speech synthesizers) should be individualized and adequate training and support provided as required.

Palliative care and end of life

A palliative care approach should be incorporated into the care plan for patients and caregivers from the time of diagnosis. The purpose of palliative care is to maximize the quality of life of patients and families by alleviating symptoms, providing emotional, psychological and spiritual support as needed, removing obstacles to peaceful death and supporting the grieving family. Timely reference to a specialist palliative care team is appropriate. Community-based palliative care or through hospital contacts (e.g. home care teams) can proceed in collaboration with the clinic multidisciplinary neurological care. A small percentage of ALS patients express interest in assisted suicide and can choose euthanasia where it is legalized.

Recommendations

- Where possible, or input from a palliative care team at the beginning of the course of the disease.
- Initiate discussions on end-of-life decisions when the patient requests or provides an opportunity for discussion on the provision of information and/or interventions at the end of the life cycle.
- Discuss options for respiratory support and end-of-life problems if the patient has dyspnea, other symptoms of hypoventilation or a forced vital capacity less than 50%.
- Inform the patient of the legal situation regarding advance directives and the naming of a health proxy. Off assistance in the formulation of an advance directive.
- Re-discussing patient preferences for life maintenance treatments every 6 months.
- Promptly start referring to hospice or homecare teams well in advance of the ALS terminal phase.
- Be aware of the importance of spiritual issues for quality of life and therapeutic choices. Establish a connection with local pastoral workers to be able to respond to the needs of the patient and relatives.
- For the symptomatic treatment of dyspnea and/or intractable pain, use opioids alone or in combination with benzodiazepines if anxiety is present. Titration of doses against clinical symptoms rarely, if ever, will result in potentially lethal respiratory depression.
- Terminal restlessness and confusion due to hypercapnia can be treated with neuroleptics (eg chlorpromazine 12.5 mg every 4-12 hours p.o., i.v., or p.r.).
- Use oxygen only if symptomatic hypoxia is present

Future developments

Since it is a syndrome with low incidence and short survival, most recommendations are based on the consensus of ALS experts. Further randomized and double-blind clinical trials are urgently needed to improve the management of ALS.

Further research recommendations (medical and psychosocial):

- Further studies of biomarkers (imaging, proteomics and metabolomics of cerebrospinal fluid and blood, neurophysiological markers) to assist in the early diagnosis of ALS and to monitor the possible effects in clinical studies.
- Further studies on the impact of specialized MND clinics on clinical outcomes, quality of life and carers' burden.
- Further studies to optimize the symptomatic treatment of muscle cramps, smears and bronchial secretions in patients with ALS.
- Better criteria to define the use of PEG, PRG, NIV and IMV.
- Further studies to evaluate the effects of PEG/PRG, cough devices and support for ventilation on quality of life and survival.
- Further studies to assess language dysfunction and its treatment in ALS.
- Systematic studies to assess cognitive impairment and frequency of frontal lobe dysfunction in ALS and standardize clinical, neuropsychological and neurodifferential methods in this field. The future diagnostic criteria of ALS should include parameters concerning cognitive dysfunction and dementia.
- Studies on the medical-economic impact of more expensive procedures (NIV, IMV, cough devices, advanced communication equipment).
- Further studies to harmonize ALS centers patient databases.
- Finally, further studies are needed on the psychosocial and spiritual determinants of the quality of life of patients and their family carers, as well as studies on the prevalence and determinants of desires

Synopsis

Multidisciplinary support for people with ALS. Interdisciplinary approaches to symptom management. Treatment Options Issue

Healthcare and support	professionals involved
Diagnosis communication	Neurologist-family doctor-psychologist
Farmacology (Rilutek)	Neurologist/rehabilitation doctor
Nutrition problems (Nutrition tube Saliva management)	Gastroenterologist pathologist dietitian
Difficulty breathing Breathing assisted Respiratory system	Specialized therapist/nurse
Palliative care team	Medicines Neurologist/General practitioner Botox Neurologist
Mobility/movement problems	Mobility equipment physiotherapist Professional therapist Specialized at ALS
Cognitive behavior and mood problems (Advice and support for patients and family members)	Neuropsychologist - psychologist
Self-care Assistance equipment	Professional therapist/nurse specialist at ALS
Limited verbal communication Alternative communication devices	Pathologist Professional therapist Specialized at ALS
Care givers support Advice and support for patients and family members	Psychologist-psychotherapist Social worker/therapist prepared for ALS issues
Sadness and loss Advice and support for patients and family members	Psychologist/social worker/prepared for ALS issues

Conclusion

The path described above of the ALS, is a real path full of obstacles and uphill. It is characterized by continuous changes and challenges, by engaging reactions and necessary adaptations, which takes into account an experience lived with patients who have given their battle with the disease. Living this condition they taught us how important it is to accept the help of others, to face suffering, to live life with dignity. It is a lesson that gives us the paradigm of expressing emotions, courage and determination, of loving life despite suffering [1-12].

All the protagonists of the stage, (patient, relatives, friends, acquaintances, neighbors, assistants), who initially approach the person with ALS, must enter this adventure keeping in mind that we are not approaching the disease, but an individual with his past, totally intact mentally. Dealing with illness-related disorders, means relating first and foremost to a person, his past, his feelings and emotional experiences, his perplexities, his character his beliefs, his interests, his abilities, his potentiality and its habits.

It becomes obvious that the first contact with the sick person will be accompanied by feelings of anguish and fear. However, these must also leave the necessary space for attitudes of understanding and respect for the person as a whole. First of all, an adequate knowledge of the disease and its implications on the person and his caregivers is desirable. A knowledge of clear and respectful communication methods; it is necessary to express feelings of esteem and admiration for the ability to live with the disease while maintaining attachment to life, uttering words of encouragement by understanding and accepting (even silence can be an adequate form of respect and communication) negative moments in which anger and despair take over.

Sharing moments of daily life easily leads those who have approached the patient, to reflect on the meaning of life and often on revisions on personal values. Living experiences of this kind, we find ourselves re-considering family, affections, health and in general the sometimes incredible adaptive potential of the human person.

You can enter a dimension where, alongside pain and suffering, fatigue, exhaustion and anger, you can discover the strength of life.

Indeed, emotional relationships play an essential role in the quality of life of all family members. In particular, clinical experience shows that if the affective climate preceding the onset of the disease was strong and solid, with the disease it becomes even more so. Never does the disease destroy or wear off strong emotional relationships. Although family affective relationships are put to the test, only fragile, unstable or already in crisis relationships before the disease are strongly at risk of being devastated and tend to worsen as it progresses.

Alongside numerous examples of availability, closeness, great affection and courage in the family environment, sometimes we come across family stories in which loneliness, abandonment, neglect, surrender and defeat prevail and in which suffering, emotional emptiness, profound anger and despair make any intervention of help very difficult.

However, life experiences may differ, illness is a condition that inevitably leads those who live it and the world around them, to questioning.

In a society in which themes such as eternal youth, beauty, power and efficiency prevail and there is a tendency to distance oneself from everything that can represent pain, suffering, loss and death, the reality of life, and in particular the reality-disease, forces one to deal with these issues and to rediscover values such as respect for life in all its forms, family union, friendship, solidarity and spirituality. In difficult conditions the presence of strong values helps us to live fully; among these values we believe that spirituality is an important one worthy of being rediscovered.

Lastly, religious faith could serve as a point of support for the sick people who believe; it is thanks to faith that they find answers to their questions, giving meaning to their suffering and make peace with loss and approaching death. These so delicate final stages of human existence, even if feared when they are experienced thanks precisely to faith and religiosity, they are conceived not as "the end" but as a moment of transition.

Concluding this work, it is necessary to underline that, even in full awareness it is not possible to fully understand the experiences and the suffering of the patients of this particular disease and their families. In the meantime, empathy and professional experience allow us to be able to see with objectivity and lucidity, allowing operators and specialized persons to provide indications, suggestions and interpretative paths useful to face the difficulties imposed by the duration and progression of the disease.

Bibliography

1. OMS. "International classification of Functioning, Disability and Health (ICF)". Erickson, Trento (2001).
2. Kiernan MC., *et al*. "Amyotrophic lateral sclerosis". *Lancet* 377.9769 (2011): 942-955.
3. Caga J., *et al*. "A longer diagnostic interval is a risk for depression in amyotrophic lateral sclerosis". *Palliative and Supportive Care* 13.4 (2015): 1019-1024.
4. Lillo P., *et al*. "How common are behavioural changes in amyotrophic lateral sclerosis?" *Amyotrophic Lateral Sclerosis* 12.1 (2011): 45-51.
5. Miller RG., *et al*. "Practice parameter update: the care of the patient with amyotrophic lateral sclerosis: multidisciplinary care, symptom management, and cognitive/behavioral impairment (an evidence-based review): report of the Quality Standards Subcommittee of the American Academy of Neurology". *Neurology* 73.15 (2009): 1227-1233.
6. Jackson CE., *et al*. "Symptom management and end-of-life care in amyotrophic lateral sclerosis". *Neurologic Clinics* 33.4 (2015): 889-908.
7. Aoun SM., *et al*. "Receiving the news of a diagnosis of motor neuron disease: what does it take to make it better?" *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration* 17.3-4 (2016): 168-178.
8. Aoun SM., *et al*. "Motor neurone disease family carers' experiences of caring, palliative care and bereavement: an exploratory qualitative study". *Palliative Medicine* 26.6 (2012): 842-850.
9. Miller RG., *et al*. "Practice parameter update: the care of the patient with amyotrophic lateral sclerosis: drug, nutritional, and respiratory therapies (an evidence-based review): report of the Quality Standards Subcommittee of the American Academy of Neurology". *Neurology* 73.15 (2009): 1218-1226.
10. Francesco Pagnini., *et al*. "Clinical Psychology and Amyotrophic Lateral Sclerosis". *Frontiers in Psychology* 1 (2010): 33.
11. Jane Alana., *et al*. "Is psychological stress a predisposing factor for amyotrophic lateral sclerosis (ALS)? An online international case-control study of premorbid life events, occupational stress, resilience and anxiety". *PLoS One* 13.9 (2018): e0204424.
12. Jessica de Wit., *et al*. "A blended psychosocial support program for partners of patients with amyotrophic lateral sclerosis and progressive muscular atrophy: protocol of a randomized controlled trial". *BMC Psychology* 6.1 (2019): 20.

Volume 8 Issue 12 December 2019