

Mental Health of People with Amyotrophic Lateral Sclerosis and Potential Interventions

Xiqiao Jiang

Royal Grammar School Guildford, Nanjing, China

npittsi50518@student.napavalley.edu

Abstract. Amyotrophic lateral sclerosis (ALS) is a fatal neurodegenerative ailment. It is the most typical type of motor neuron disease seen in adults. The average survival time is 3 to 5 years after diagnosis. ALS patients might suffer from mental illnesses and distress, as they are conscious that their bodies are gradually deteriorating. It is most likely for them to develop mental illnesses immediately before and after diagnosis, as well as throughout the disease's early stages. This paper reviews previous researches and studies on common mental illnesses in ALS patients, which are depression and anxiety, as well as their effect on patients' quality of life. It also discusses methods to improve mental conditions of ALS patients, both for people in the vicinity of patients and the patients themselves.

Keywords: Amyotrophic lateral sclerosis, depression, anxiety, mental health.

1. Introduction

Amyotrophic lateral sclerosis (ALS) is a neurodegenerative ailment characterised by degenerating motor neurons in the body [1]. Symptoms may include but are not limited to muscle weakness and atrophy across the body, and difficulty in swallowing. These symptoms gradually increase until paralysis of the body and respiratory muscles [2]. Other than motor weakness, over 50% of patients are likely to experience cognitive or behavioural changes to some extent [3]. The average survival time is 3 to 5 years. Currently, there are no effective treatment options [4]. The optimal contemporary treatment for ALS is to synthesise knowledge across different areas to maximise patients' quality of life [3].

ALS is the most common motor neuron disease (MND) for adults [5]. It accounts for around 70% of MND cases. The mortality rate of MND was found to be 1.9 per 100,000 people annually in the world. Six thousand deaths were caused by ALS between 2011 and 2014 in the US every year [6]. There was an estimated 69% increase in ALS patients across the world, from 220,000 in 2015 to 370,000 in 2040 [5].

ALS patients often report being depressed, anxious, more stressed, and less pleasurable during the early stages of the disease. They are also at greater risk of committing suicide directly after diagnosis. Depression and many other mental illnesses do not increase with the progression of the disease and may have been rare near the end of life [3]. There is no cure for this disease, so it is necessary for others to encourage patients to live and appease their emotions [3]. This aims to improve patients' standard of living, and help them enjoy the limited time left in their lives.

The aim of this paper is to review previous journals on common mental health issues in ALS patients and the potential interventions. It will also focus on what family, friends, and the patients themselves could do to eliminate mental health issues and improve their quality of life.

2. Methodology

The academic databases of Google Scholars and CNKI were used to search the literature comprehensively. Keywords were entered as follows: "ALS" or "amyotrophic lateral sclerosis," "depression," "anxiety," "mental health," "quality of life" and "intervention." Studies were included if they: (1) referred to the introduction and definition of ALS, such as mortality rate and motor neuron disease mortality rate; (2) involved at least one of the mental health issues that could appear in ALS

patients; (3) discussed the methods of intervention with emotions, for both patients and those around them.

3. Literature Review

3.1. Common Mental Health Issues in ALS Patients

As patients lose control of their bodies, coupled with changes in their appearance, their sense of dignity will be challenged, and a sense of impotence develops. As a result, the vast majority of patients have gone through, or are going through, a stage of feeling that life is meaningless or have even developed suicidal thoughts. At the same time, the results of an interview showed that most of the patients would not confide with their family members about their negative emotions, choosing to bear them on their own and that these negative emotions, such as depressive tendencies, anxiety, and fear, could not be alleviated [7].

3.1.1 Depression

It is anticipated that ALS patients will display a high depression rate and a considerable decrease in quality of life. However, previous studies have proven that the development of mental health issues is not correlated with the progression of the disease. Depression was shown to be caused by functional and physical disabilities of the disease during diagnosis, though it has not been confirmed clinically [8].

A study by Roos et al. has found that ALS patients are more prone to suffer from depression than the control group, immediately before and after being diagnosed with ALS [9]. Results showed that individuals aged 65 and older were at higher risk of depression. The risk was most noticeable within the first year following diagnosis, whereas in the second year, it was statistically insignificant. Other factors, such as status in society, did not have much effect on the associations [9].

Some possible explanations of the relationship between preceding experience of depression and increased chance of ALS are proposed. For example, a symptom of ALS during the early stages may be depression. This contradicts the usual belief that the main symptom of ALS is motor disability. However, it is possible that other symptoms may be involved before and after the exhibition of motor disabilities [9].

ALS patients often feel more depressed, anxious, stressed, and hopeless during the early stages of the disease immediately after diagnosis. They may be at higher risk of committing suicide or having suicidal thoughts at around the same time. Depression in ALS patients was found to be anticipated through experience of the disease. For example, the uncertainty of the future or diagnostic lag, instead of conventional factors, could cause depression. There was no increase in depression found as the disease progressed, and it became more scarce toward the end of life [3].

3.1.2 Anxiety

Montel et al. had completed a study focusing on the mental wellbeing and living standard in ALS patients [10]. All participants received outpatient treatments. According to the results, feelings of anxiousness and somatic dysfunctions in patients increased over the duration of the study. As they lose their physical functions gradually, patients may feel increasingly bothered and apprehensive. The more severely injured the patients are, the more their physical abilities are limited. They also tend to be more humorous, using it as a coping technique for the disease [10].

Both the patients and their caregivers were more likely to experience anxiety directly before and after formal diagnosis, as well as in the disease's early phases. There are some possible explanations for this increase in anxiety. For example, the unpredictability of the disease, and its impact on patients' future, quality of life, and physical abilities [3].

3.2. Quality of Life

Both medical and nonmedical criteria are used to define quality of life [11]. These include and are not limited to mental conditions, autonomy level, interpersonal relationships, and individual convictions [12].

It was found that for ALS patients, only multidisciplinary care could improve their quality of life efficaciously after being diagnosed [13]. ALS support groups usually combine physicians, therapists, and social workers specialised in different areas. It is necessary for ALS patients to make essential decisions on their medication, such as the use of noninvasive ventilation. This could influence their quality of life or even their survival [3].

The topic of whether others could decide to end the lives of severely impaired patients is becoming increasingly divisive [14]. It was found that ALS patients have worse mental conditions in general than the population. The level of mental anguish in ALS patients was shown to be similar to people who suffer from mental illnesses such as depression or anxiety [15]. A study by Groenestijn et al. proved that health-related quality of life appears to share a negative correlation with anxiety [16]. A lower health-related standard of living usually correlates with increasing anxiety levels. There seems to be no correlation between global quality of life and anxiety. However, the relationship could not be disproved regarding a single study. Depression was found to share a negative correlation with health-related quality of life. This means that increased symptoms of depression are correlated with lower health-related living standard. However, a relationship between global quality of life and depression cannot be determined due to the low reliability of the results [16].

3.3. Potential Interventions

ALS affects patients' lives greatly, it can be extremely devastating psychologically with distinctive mental wellbeing challenges. Psychological disorder in ALS patients can be a significant indicator of general standard of living and disease prognosis [3]. As mentioned before, it is likely for ALS patients to suffer from severe anxiety during the early stages of diagnosis. Thus, it is necessary for medical providers to be aware and intervene effectively to help relieve this distress [3].

3.3.1 Family and Friends

In the early stages of diagnosis, caretakers often experience emotions such as denial and anxiety. As treatment progresses and the conditions change, emotions gradually shift to acceptance, and they may spend more time accompanying the patients [2]. It is found that caretakers are often under greater emotional stress and burden. Therefore, they should actively adjust their attitude and pay attention to their own emotional state before trying to improve ALS patients' mental states. At the same time, they should seek to learn more about the disease. Being able to recognise the basic symptoms and master the emergency measures is also important in order to take better care of patients [2].

3.3.2 ALS Patients

Viktor Frankl proposed Logotherapy based on his experience in the concentration camps. He believed that people have the ability to overcome the frustrations they experience and be able to realise the meaning of their lives. Patient coping strategies can be broadly categorised into three values [4].

Experiential values refer to discovering the meaning and value in life after an experience. Patients could find it difficult to accept the outcome of their diagnosis. This helps them to rationalise the attribution of the causes of their disease. It also helps to increase their sense of control over the disease so they can better cope with it [4].

Creative values can be used to find the meaning of life by finding a job or pursuing a career. This helps patients enjoy their previous interests and discover new hobbies, encouraging them to fill their restricted lives and relax [4].

Attitudinal values were the third way of seeking meaning in life. For example, the kind of attitude people adopt when they face something. Patients tend to be grateful and think more positively after hearing stories of people less fortunate than themselves [4].

4. Implications

As mentioned before, it is controversial whether to allow others to end the lives of severely impaired patients [14]. Patients' quality of life could be an important factor to consider regarding this decision. Logotherapy encourages patients to discover the meaning and value of life. This aims to inspire positive thinking in patients and improve their living standard [4]. As the disease progresses to the middle and late stages, patients rely on others heavily to live [2]. Thus, patients' quality of life could be an important factor regarding the decision to ending their lives. If patients feel hopeless or have a substandard quality of life, others may consider ending their lives. This is to stop patients from suffering in the disease's later phases, because they cannot enjoy their lives and have to live in desperation every day. However, other factors must be considered simultaneously as well, such as the medical support available and the socio-economic status of the family. For example, if the family could afford better care for the patients, they would not end the patients' lives but instead try to improve the mental conditions of patients.

To enhance patients' psychological well-being, they could discover the meaning of their lives and try to fill their time with activities [4]. One Perspective of logotherapy is attitudinal value, which is to tell patients about stories of people less fortunate than them [4]. Thus, patients may save their lives and become more optimistic. This facilitates them to adjust their mindsets and accept the treatments more positively.

It is also necessary for others around the patients to offer mental support, such as medical personnel, social workers, or the community. Medical personnel should actively pay attention to the psychological changes of patients. These could be through network interventions, such as telephone follow-up, in order to give appropriate encouragement [2]. On the other hand, the community, as a key link in the continuity of care, should build an integrated care support system. This could reduce the burden on patients and their families and improve patients' quality of life [2].

Since there is an estimated increasing tendency of people diagnosed with ALS, more research should focus on the mental health of ALS patients and how to intervene. More methods on how people around the patients could take care of their psychological well-being and how patients themselves can cope with existing negative emotions should be researched.

5. Conclusion

ALS is a fatal neurodegenerative disease with no effective treatments. Patients gradually lose control of their bodies, and their appearance changes simultaneously as the disease progresses. Thus, it is likely for ALS patients to experience negative emotions, suffer from mental illnesses, or develop suicidal thoughts.

This paper identified two of the main mental conditions in ALS patients, which are depression and anxiety. Although it is expected that ALS patients will show a higher depression rate as the disease progresses, this has been proven to be false. ALS patients often experience more negative emotions immediately after diagnosis or during the disease's early stages. Montel et al. found that feelings of anxiousness in ALS patients increase as their study and the disease progresses. This may be caused by factors such as the uncertainty of the disease. The living standard of ALS patients can only be improved by adopting multidisciplinary care. Therefore, it will be necessary for patients to make decisions on medication as it will affect their quality of life.

It is likely that the caretakers or friends of ALS patients feel stressed because of the disease. Thus, they may have to alter their own mental states before offering help to the patients. Logotherapy may be a method to improve ALS patients' mental conditions. It aims to help patients find meaning and

value in life, as it improves patients' quality of life and their mental conditions. It is also necessary for others, such as social workers, community, and medical personnel, to provide mental support for ALS patients. This can be through online follow-up or by building a system of integrated care by the community. ALS patients' quality of life may be an important determinant of whether to end the patients' lives. However, there are other factors to consider at the same time, such as the availability of medical support or the socio-economic status of the family.

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