Psychology of patients with amyotrophic lateral sclerosis (ALS) compared with that of cancer patients

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Objectives: Psychological characteristics of patients with amyotrophic lateral sclerosis (ALS) were compared to those of cancer patients and of healthy volunteers to objectively evaluate anxiety among patients with ALS.

Methods: The battery that was employed consisted of the Manifest Anxiety Scale (MAS) and State-Trait Anxiety Inventory (STAI) tests.

Results: MAS assessment showed high-level anxiety more frequently in the ALS group compared with that in the cancer group. According to the STAI scores, the ALS and healthy groups had high trait-anxiety scores, while the cancer group had high state-anxiety scores. The state-anxiety scores were significantly higher in the ALS and cancer groups compared with those in the healthy group. The trait-anxiety scores were highest in the ALS group and significantly higher in the ALS group compared with those in the healthy group. Both the state-anxiety and trait-anxiety levels were often high in the ALS group. The cancer-nondisclosed group often had high levels of trait anxiety.

Conclusions: ALS patients often consciously or unconsciously felt anxious and were in a discouraged state. How to perceive anxiety arising in these patients in difficult situations and how to reduce such anxiety are important factors in improving the quality of life of patients with ALS.

Key words: amyotrophic lateral sclerosis, Manifest Anxiety Scale, State-Trait Anxiety Inventory

Introduction

To objectively evaluate the psychological aspect of anxiety in patients with amyotrophic lateral sclerosis (ALS), which is characterized by rapid disturbances of extremity and trunk motor function without accompanying consciousness or intelligence disorders, we compared the findings of the psychological assessments of anxiety for patients with ALS with those for patients with cancer (both groups facing death), and with those for age-matched healthy volunteers.

Patients

The ALS group

Ten patients who were clinically diagnosed with ALS1,2 were selected for the ALS group. These patients showed mild bulbar paralysis, even when reductions in respiratory muscle strength were noted, and were capable of psychological approach through conversation. Informed consent was obtained from all patients. There were 7 men and 3 women for whom the ages of disease onset were 41 to 76 years old (mean, 56.8 years old). Their durations of sickness ranged from 7 to 47 months (mean, 16.4 months), and the ages at the time of assessments were 43 to 77 years old (mean, 58.8 years old).

The cancer control group

Twenty patients with cancer were selected for the control group. Informed consent as to the cancer diagnosis was obtained from 8 patients (the cancer-disclosed group). The cancer-disclosed group consisted of 7 men and 1 woman; their ages at the time of assessment ranged from 50 to 71 years old (mean: 61.3 years old). The primary sites of cancer were liver in 3 cases, stomach in 4, and the large bowel in 1 case. Informed consent as to cancer
diagnosis was not obtained from 12 patients (the cancer-nondisclosed group), and this group consisted of 8 men and 4 women. Their ages at the time of assessments ranged from 41 to 73 years old (mean: 57.8 years old). The primary cancer sites were the liver in 4 cases, the gallbladder/bile duct in 2 cases, the pancreas in 1 case, the stomach in 4, and the large bowel in 1 case.

The healthy control group
Seventy healthy volunteers of ages that matched those of the patients in the other groups (50s and 60s) were selected for the healthy group. The number of subjects in their 50s and 60s were 39 and 31, respectively. These included 39 men and 31 women (age, 50−59 years old: 24 men and 15 women; age 60−69 years old: 7 men and 24 women). Their ages at the time of the assessments were 50 to 69 years old (mean: 58.3 years old).

Methods
The test battery used for assessing state, symptoms, and anxiety consisted of the following: the Manifest Anxiety Scale (MAS, [the Japanese version of the Minnesota Multiphasic Personality Inventory and the Manifest Anxiety Scale, Abe and Takaishi, 1968],3 and the State-Trait Anxiety Inventory (STAI, [Nakazato and Mizuguchi, 1982]).4 We calculated the averages and standard deviation (SD) of the STAI results. The results were then statistically examined using the t-test.

Results
Table 1 shows the results for the MAS test. In the ALS group, the percentage of patients having high-level anxiety (Levels I and II) was 77.7%. This percentage was 33.3% among patients with cancer (in both the cancer-disclosed and -nondisclosed groups). Therefore, high-level anxiety was seen more frequently in patients in the ALS group than in the cancer groups.

Table 2 shows the STAI mean scores. In the ALS group, the score was higher for trait anxiety that for state anxiety. In the cancer groups, regardless of whether cancer was disclosed to the patients or not, the score was higher for state anxiety than for trait anxiety. The score for state anxiety was highest in the cancer-disclosed group, followed by the cancer-nondisclosed group, and then the ALS group, and was lowest in the healthy group (Figure 1). The state anxiety score for the healthy group differed significantly from those in the cancer-disclosed (P < 0.01), cancer-nondisclosed (P < 0.01), and ALS groups (P < 0.02). The trait anxiety score was the highest in the ALS group, and the cancer-disclosed group scores were higher than those in the cancer-nondisclosed group, while those in the cancer-nondisclosed group were higher than those in the healthy group, which was the lowest, with the difference between the ALS and the healthy groups being statistically significant (P < 0.02, Figure 2).

As assessed by STAI, the scores for both state anxiety and trait anxiety were often high in the ALS group (Table 3). In the cancer groups, the cancer-disclosed group often had a high level of state anxiety, while the cancer-nondisclosed group often had high level of trait anxiety.

Table 1. Manifest Anxiety Scale (MAS) data

<table>
<thead>
<tr>
<th>Levels</th>
<th>Cancer groups</th>
<th>ALS group</th>
<th>Disclosed</th>
<th>Nondisclosed</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>4 (44.4%)</td>
<td>2 (33.3%)</td>
<td>2 (33.3%)</td>
<td></td>
</tr>
<tr>
<td>II</td>
<td>3 (33.3%)</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>III</td>
<td>2 (22.2%)</td>
<td>1 (16.6%)</td>
<td>3 (50.0%)</td>
<td></td>
</tr>
<tr>
<td>IV</td>
<td>0</td>
<td>1 (16.6%)</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>V</td>
<td>0</td>
<td>2 (33.3%)</td>
<td>1 (16.6%)</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>9</td>
<td>6</td>
<td>6</td>
<td></td>
</tr>
</tbody>
</table>

I, high-level anxiety; II, considerably high-level anxiety; III-V, normal

Table 2. Data on mean State-Trait Anxiety Inventory scores

<table>
<thead>
<tr>
<th>Anxiety</th>
<th>ALS group (n = 10)</th>
<th>Cancer group (n = 20)</th>
<th>Healthy group (n = 70)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Disclosed (n = 8)</td>
<td>Nondisclosed (n = 12)</td>
<td></td>
</tr>
<tr>
<td>State</td>
<td>42.300 ± 9.673*</td>
<td>49.750 ± 12.116**</td>
<td>46.750 ± 13.626**</td>
</tr>
<tr>
<td>Trait</td>
<td>46.900 ± 9.515***</td>
<td>45.000 ± 10.502</td>
<td>43.167 ± 12.925</td>
</tr>
</tbody>
</table>

*P < 0.02, **P < 0.01, ***P < 0.01 (t-test)
Bars represent mean values, and error bars represent SD. *P < 0.05, **P < 0.01 (t-test)

**Figure 1.** Data on State-Trait Anxiety Inventory (STAI) scores (state anxiety)

Bars represent mean values, and error bars represent SD. *P < 0.05 (t-test)

**Figure 2.** Data on mean STAI scores (trait anxiety)
According to the STAI interpretation, state anxiety is defined as a temporary emotional state that can vary depending on the given living conditions for individuals, while trait anxiety, which reflects the individual’s tendency to respond to an experience with an anxious state, is a relatively stable personality tendency of individuals. Therefore, the results of the present psychological assessment of anxiety suggested that patients with ALS were in a state that was precursory to anxiety and that they did not directly express anxiety despite sufficient feelings of anxiety.

Although the current levels of anxiety were less severe in patients with ALS than in those with cancer, the likelihood for patients to become more anxious seemed to be higher in patients with ALS than in those with cancer. Moreover, the analysis of the patients’ anxiety levels assessed with STAI revealed that the ALS group presented with characteristics of anxiety that were seen in both the cancer-disclosed and -nondisclosed groups. It is noteworthy that the patients with ALS showed a psychological state of anxiety resembling that seen in cancer-nondisclosed patients. Although ALS patients feel anxious of their progressive disease, and are in a
state precursory to very high levels of anxiety, the current level of anxiety among these patients was not expressed as much as that in cancer-disclosed patients. This seemed to illustrate the psychological characteristic of patients with ALS who are unlikely to express anxiety directly as well as indicating a problem with informed consent.

Regarding informed consent, the problems appear to be associated with the healthcare professionals who give the patients the information about their cases, as well as with the patients themselves. Generally, when a patient receives a diagnosis of cancer, it is most likely thought of as being terminal; while patients receiving a diagnosis of ALS do not usually equate it to a death sentence. Such a difference in the general public’s apprehension between cancer and ALS may be problematic.

Our previous study of patients with ALS using the Rorschach test and the STAI suggested that ALS patients probably deal with anxiety in the following ways. 1. restriction of stimuli (receiving less stimuli from surrounding people), 2. emotional shutout (avoiding awareness of negative emotions), 3. suppressive posture (suppression of the expression of the emotions one is aware of), and 4. reduction of anxiety (attempting to reduce anxiety by behaving cheerfully).

Patients with ALS who have such psychological characteristics regarding anxiety tend to lose objects and mask emotional responses (grief responses) in order to deal with their anxiety. They often exhibit physical expressions (headache, dizziness, palpitations, difficulty in breathing, etc.), obsessive-compulsive attachments to device and/or commodity arrangements, minor changes, and deformed self-assertion instead of exhibiting the usual psychological characteristics related to grief responses. For healthcare professionals, it is important to quickly perceive the anxiety of patients with ALS who exhibit such expressions and to make efforts to help these patients accept their disease, which in turn should help reduce their anxiety. To this end, it is essential that healthcare professionals completely assure the patients that the professionals always support the patients and provide safety controls to protect each patient’s life. Psychological support seems to play a significant role in this process (Figure 3).

Reports on the psychology of ALS patients were rare until the first half of the 1990s when we summarized this report. However, several reports have been published since 2000.

In conclusion, psychological assessments of anxiety were made for 10 patients with ALS, 20 patients with cancer, and 70 healthy volunteers. The test battery consisted of the MAS and the STAI. As per the MAS assessment, the percentage of patients who had high-level anxiety was higher in the ALS group than that in the cancer group. When assessed with the STAI, the ALS and healthy groups had high scores for trait anxiety, while the cancer group had high scores for state anxiety. The state anxiety score on the STAI was significantly higher in the ALS group and cancer groups than in the healthy group. The trait anxiety score on STAI was the highest in the ALS group, and the score for the ALS group was significantly higher than that for the healthy group. The STAI scores indicated that patients with ALS often had high levels of both state anxiety and trait anxiety, while cancer-disclosed patients often had high levels of state anxiety, and cancer-nondisclosed patients often had high levels of trait anxiety. Patients with ALS feel anxious both consciously and unconsciously and are in a discouraged state. How to perceive the anxiety arising in these patients during difficult situations and how to reduce such anxiety are important factors for improving the quality of life of patients with ALS.

Acknowledgments

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Professor Emeritus Hisayuki Kowa passed away on November 23, 2012. This paper was written on the basis of the reports we wrote while Prof. Kowa was a member of the Research Committee of CNS Degenerative Diseases, Ministry of Health and Welfare. The paper reflects part of the presentation that was made by Prof. Kowa at the 38th General Conference of the Societas Neurologica Japonica in 1997 (May 14-16, Yokohama) for which he served as the Chairman. We have translated the report into English in honor of the late Professor Emeritus Hisayuki Kowa. May he rest in peace.

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References