Original Contribution Kitasato Med J 2014; 44: 12-16

Psychology of patients with amyotrophic lateral sclerosis (ALS) compared with spinocerebellar degeneration, Parkinson's disease, and cerebrovascular disease

Masafuchi Ryoh,[1] Kazuko Hasegawa,[2] Yoshitsuna Fukuyama,[3] Fumihiko Sakai,[4] Norihisa Furuhashi,[5] Kazutoshi Nishiyama,[1] Hisayuki Kowa[1]

[1] Department of Neurology, Kitasato University School of Medicine
[2] Department of Neurology, National Hospital Organization, Sagamihara National Hospital
[3] Sagamihara Counseling Room
[4] Saitama Neuropsychiatric Institute, Saitama International Headache Center
[5] The Nukada Institute for Medical and Biological Research

Objectives: Psychological assessments were conducted to objectively evaluate the psychology and views of sickness and health in patients with neurological disease.
Methods: Patients were divided into an amyotrophic lateral sclerosis (ALS) group, a spinocerebellar degeneration (SCD) group, a Parkinson's disease (PD) group, and a cerebrovascular disease (CVD) group. Evaluations were made with the Center for Epidemiologic Studies Depression Scale, the State-Trait Anxiety Inventory, and the Japanese version of the Health Locus of Control.
Results: Depressed mood was often observed in patients in the ALS and SCD groups. The trait anxiety scores were high in each group with the highest score in the SCD group and the lowest score in the CVD group.
Conclusions: Regarding the causes and future courses of their disease, patients in the PD and CVD groups tended to think that they could deal with their disease themselves with support from surrounding people, while patients in the ALS and SCD groups tended to think it unlikely to deal with their diseases by relying on themselves or healthcare professionals. The psychological statuses of patients and their approach to improving their quality of life or dealing with the disease varied depending on each patient's view about their disease.

Key words: amyotrophic lateral sclerosis, spinocerebellar degeneration, Parkinson's disease, cerebrovascular disorder, Center for Epidemiologic Studies Depression Scale, State-Trait Anxiety Inventory, Health Locus of Control

Introduction

When dealing with patients with neurological disease for which few valid means of treatment are available despite the evident awareness of the patient's compromised activities of daily living, it seems important to select a treatment approach that is tailored to individual patients according to a thorough understanding of their desires, psychological status, and views about health and illness. We evaluated anxiety levels among patients with amyotrophic lateral sclerosis (ALS) and reported the possibility that they have specific anxiety disorders.[1,2] We subsequently attempted psychological assessments in order to objectively evaluate the psychological statuses and views of health and illness among patients with neurological disease, especially those with ALS.

Patients

The study involved 59 patients in four groups: 10 patients with ALS, 11 with spinocerebellar degeneration (SCD), 27 with Parkinson's disease (PD), and 11 patients with cerebrovascular disease (CVD).

The ALS group consisted of 9 patients who had been clinically diagnosed with ALS[3,4] and 1 patient who had been diagnosed with spinal progressive muscular atrophy (SPMA). Informed consent was obtained from all of these patients. Dementia was absent, paralysis of the

Received 16 April 2013, accepted 24 April 2013
Correspondence to: Masafuchi Ryoh, Department of Neurology, Kitasato University School of Medicine
1-15-1 Kitasato, Minami-ku, Sagamihara, Kanagawa 252-0374, Japan
E-mail: ryo-yang@kitasato-u.ac.jp

respiratory muscles was mild, and psychological assessments through conversation were possible in all cases. There were 6 males and 4 females, with ages of disease onset of 30 to 73 years old [mean ± standard deviation (SD), 57.4 ± 15.5]. Their durations of sickness were 1 to 8 years (mean ± SD, 2.9 ± 2.1 years), and their ages at the time of assessment were 37 to 74 years old (mean ± SD, 60.3 ± 13.9).

The SCD group consisted of 11 patients who had been clinically diagnosed with SCD. Informed consent was obtained from each patient, and psychological assessments through conversation were possible in all cases. Five patients had positive family histories. There were 5 males and 6 females with ages of disease onset of 20 to 63 years old (mean ± SD, 42.0 ± 13.9). Their durations of sickness were 3 to 33 years (mean ± SD, 10.0 ± 9.9 years), and their ages at the time of assessment were 41 to 67 years old (mean ± SD, 52.0 ± 9.4 years).

The PD group consisted of 27 patients who had been clinically diagnosed with PD, including 2 cases with juvenile PD, 4 cases with familial PD, and 21 cases with essential PD. Written informed consent was obtained from all the patients. Dementia was absent, and psychological assessments through conversation were possible. The severities that were rated according to the Hoehn and Yahr classification were II in 4 cases, III in 13 cases, and IV in 10 cases. There were 14 males and 13 females with ages of disease onset of 23 to 76 years old (mean ± SD, 53.0 ± 11.3 years). Their durations of sickness were 3 to 27 years (mean ± SD, 10.1 ± 5.9), and their ages upon assessment were 47 to 79 years old (mean ± SD, 63.1 ± 7.9).

The CVD group consisted of 11 patients in whom dementia and aphasia were absent and psychological assessments through conversation were possible. Three patients had bleeding (subcortical, pontine, or putaminal hemorrhages). Seven patients had infarctions (middle cerebral artery-perfused area, brainstem, or multiple infarctions). One patient had transient amnesia. There were 7 males and 4 females with ages of disease onset of 41 to 79 years old (mean ± SD, 58.0 ± 9.1). Their durations of sickness were 1 to 14 years (mean ± SD, 4.8 ± 3.7), and their ages at the time of assessment were 41 to 79 years old (mean ± SD, 62.8 ± 9.1).

Methods

The test battery consisted of the following three components: the Center for Epidemiological Studies Depression Scale (CES-D),[5] the State-Trait Anxiety Inventory (STAI),[6] and the Japanese version of the Health Locus of Control (JHLC).[7] The tests were conducted through interviews by a clinical psychologist.

Results

The CES-D data showed that the mean scores were high in the ALS and SCD groups (Table 1). Seven patients (70%) from the ALS group and 9 patients (82%) from the SCD group were rated as having the possibility of being depressed.

The STAI data in Table 2 shows the mean scores. In all the patients, the scores for trait anxiety were higher than those for state anxiety. The score was highest in the SCD group, and that in the CVD group was lower than those in any other group. In the evaluation of anxiety

Table 1. Mean CES-D (Center for Epidemiologic Studies Depression Scale) scores

	ALS group	SCD group	PD group	CVD group
Mean scores ± SD	20.3 ± 8.3	37.1 ± 20.1	14.3 ± 7.4	17.1 ± 11.2
Depression cases	7 (70.0%)	9 (81.8%)	10 (37.0%)	4 (36.4%)

Note: The depression cases were cases with the scores below 16 (the cut-off point).

Table 2. Mean STAI (State-Trait Anxiety Inventory) scores

Anxiety	ALS group	SCD group	PD group	CVD group
State anxiety	40.5 ± 11.6	42.5 ± 7.7	40.7 ± 11.5	33.4 ± 7.5
Trait anxiety	42.0 ± 12.5	48.9 ± 13.3	47.4 ± 12.0	37.6 ± 8.4

Scores are means ± SD.

Table 3. Anxiety levels assessed with STAI and number of cases

	ALS group		SCD group		PD group		CVD group	
	State anxiety	Trait anxiety	State anxiety	Trait anxiety	State anxiety	Trait anxiety	State anxiety	Trait anxiety
I	0	1 (10%)	0	0	0	0	0	0
II	3 (30%)	2 (20%)	0	1 (9.0%)	6 (22.2%)	2 (7.4%)	5 (45.5%)	4 (36.4%)
III	2 (20%)	2 (20%)	6 (54.5%)	4 (36.4%)	10 (37.0%)	10 (37.0%)	5 (45.5%)	5 (45.5%)
IV	2 (20%)	3 (30%)	3 (27.3%)	2 (18.2%)	5 (18.5%)	7 (25.9%)	0	2 (18.2%)
V	3 (30%)	2 (20%)	2 (18.2%)	4 (36.4%)	6 (22.2%)	8 (29.6%)	1 (9.0%)	0

I and II, low; III, average; IV, high; V, very high

Table 4. Japanese version of the Health Locus of Control

Category	ALS group	SCD group	PD group	CVD group
Oneself	19.1 ± 5.8	21.3 ± 6.4	23.1 ± 4.0	24.6 ± 3.1
Family	20.6 ± 5.7	17.1 ± 7.0	22.5 ± 4.5	24.0 ± 2.8
Professionals	18.2 ± 4.5	15.5 ± 6.2	19.7 ± 2.9	21.8 ± 4.2
Chance/accidental event	17.5 ± 7.0	17.0 ± 5.4	17.8 ± 4.8	16.1 ± 5.6
Supernatural phenomena	9.2 ± 4.0	9.7 ± 3.6	11.9 ± 5.1	10.0 ± 5.5

Scores are means ± SD

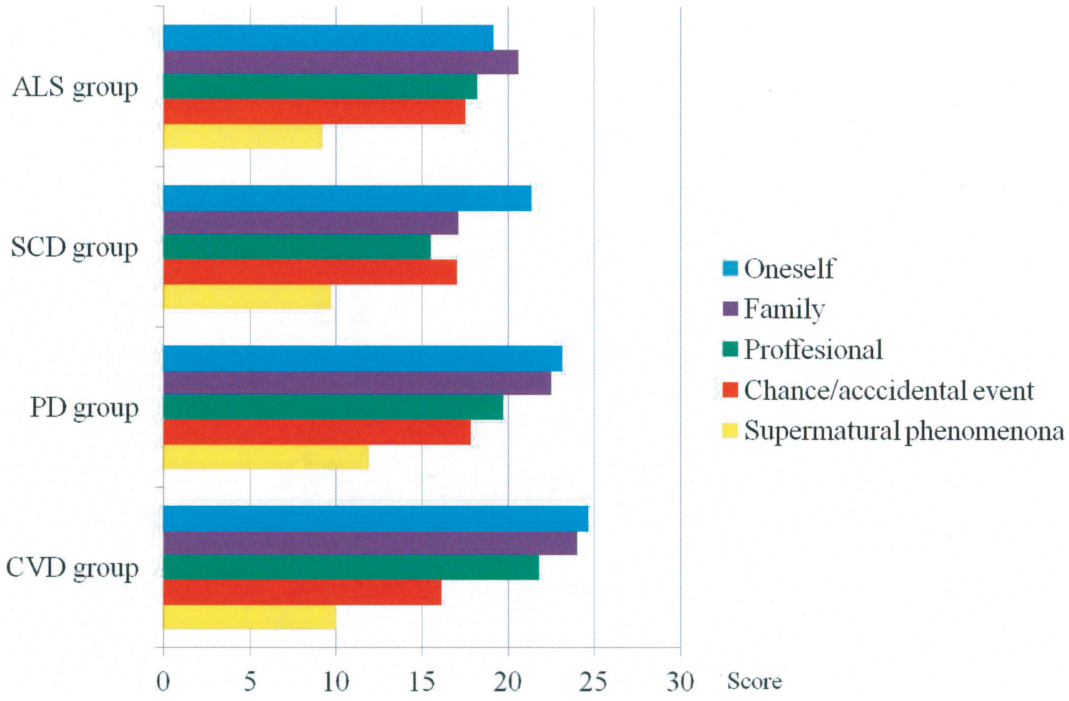

Figure 1. JHLC (Japanese version of the Health Locus of Control) graph

level (Table 3), the percentage of patients having high-level anxiety (Levels V and VI) was very low in the CVD group.

The JHLC data in Table 4 show the mean scores for each factor in each group. In the ALS group, the family score was the highest. In the other groups, the scores for the patient's own factors were the highest. Figure 1 graphically represents the mean scores recorded. Although the PD group and the CVD group showed a similar pattern of self-identification, the scores were relatively low in the ALS and SCD groups. In the ALS group, the scores were high for family factors. And in the SCD group, the scores were particularly low for professional factors.

Summarizing the results, gives the percentages of patients that were rated as depressed were high in the ALS and SCD groups. And although anxiety was seldom experienced in patients in the CVD group, patients with neurodegenerative disease tended to be frequently aware of anxiety. Moreover, in the CVD and PD groups, there was a tendency to expect contributions to their health and sickness from patients themselves and the surrounding people (family members and healthcare professionals, among others), while the ALS and SCD groups had lower expectations from healthcare professionals. Furthermore, the ALS group had high expectations of contributions to health and sickness from family members.

Discussion

In patients with CVD who showed no progression of symptoms, the levels of depression and anxiety were low, and it was possible for the patients themselves to deal with the causes and prognoses of their disease. These patients felt that they could receive valid support from surrounding people (family members and healthcare professionals, among others).

In patients with PD who showed a progression of symptoms, but who were aware of the possibility of achieving some levels of activities of daily living by means of medication, anxiety was present, but it was possible for the patients themselves to deal with the causes and prognoses of the disease. These patients felt that they could receive valid support from surrounding people.

For these two diseases, CVD and PD, it is desirable to improve the psychological statuses of patients through enriching drug therapy, device availability, and social welfare, in addition to the development of causative therapy. However, patients with SCD or ALS are often aware of their depression or anxiety, and they feel that they cannot adequately deal with their sickness by relying on themselves or healthcare professionals. This feeling probably reflects the current situation where there is hardly any means for them to be sure of their levels of activities of daily living.

Some investigators have proposed a view that the introduction of religion to the care of terminally ill patients, which is practiced overseas, could be recommended in Japan. In the present study, however, the scores for supernatural phenomena, which is similar to religion, were low in each disease group when they were assessed with the JHLC. This means that the tendency to view a disease as a supernatural phenomenon was quite weak in each disease group. In view of this finding, it is unlikely that the introduction of religion will improve the psychological statuses of patients in Japan who lack the same religious beliefs compared with patients in foreign countries, and it is necessary to adequately consider the backgrounds of individual patients.

Patients with SCD expected less from their family members and healthcare professionals; and, for these patients, chance or accidental events tended to serve as relatively important scales, suggesting that these patients faced the disease with a somewhat objective mind. Furthermore, patients with ALS had a relatively high adherence to the scale that was related to family, which probably reflected that their daily living was supported by family members and others, or that it reflected the patients' desires to maintain their daily living with such support.

Regarding these four diseases, it is desirable to elucidate the etiology as soon as possible and to make causative therapy available. For the time being, the disclosure of precise information about the etiology and treatment for these diseases seems to be a valid approach to improve the psychological statuses of these patients. As illustrated above, the psychological statuses of patients and their approach to improve their quality of life vary depending on their views of the causes of sickness and health. We suggest that individual patients have different views about sickness and health, that they have multiple views at a time, and that these views change over time, resulting in a complex sense of identification and changes over time in their psychological status (depression, anxiety, among others).

The psychological system surrounding sickness and health may be viewed as a complex one. In any event, it seems important for healthcare professionals from now on to sufficiently understand the psychological statuses of individual patients with each disease and their changes

over time and to take appropriate actions.

In conclusion, Psychological assessments were attempted in 10 patients with ALS, 11 with SCD, 27 with PD, and 11 patients with CVD. The test battery consisted of the CES-D, STAI, and JHLC tests. The possibility of depressed mood was often suggested in both the ALS and SCD groups. The scores for trait anxiety were high in each disease group with the highest and lowest scores in the SCD and CVD groups, respectively. Anxiety was seldom felt in the CVD group. Regarding the causes of disease and countermeasures, patients with PD or CVD often thought that they could deal with the disease by themselves and that they received adequate support from surrounding people. Patients with ALS or SCD, however, often thought it impossible to deal with the disease by relying only upon themselves and healthcare professionals. The psychological statuses of patients and their approaches to improving their quality of life and dealing with their diseases varied depending upon their views regarding the causes of their own individual sickness and health.

Acknowledgment

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 translated the report into English in honor of the late Professor Emeritus Hisayuki Kowa. May he rest in peace.

This study was conducted under the advisory of the Research Committee of Neuromuscular Diseases, Specific Diseases, Ministry of Health and Welfare in FY 1997.

References

1. *Annual report of the Research Committee of CNS Degenerative Diseases, the Ministry of Health and Welfare of Japan*. 1995; 240-3 (in Japanese).
2. *Annual report of the Research Committee of CNS Degenerative Diseases, the Ministry of Health and Welfare of Japan*. 1996; 74-6 (in Japanese).
3. Brooks BR. El Escorial World Federation of Neurology criteria for the diagnosis of amyotrophic lateral sclerosis. Subcommittee on Motor Neuron Diseases/Amyotrophic Lateral Sclerosis of the World Federation of Neurology Research Group on Neuromuscular Diseases and the El Escorial "Clinical limits of amyotrophic lateral sclerosis" workshop contributors. *J Neuro Sci* 1994; 124 (Suppl): 96-107.
4. *Annual report of the Research Committee of CNS Degenerative Diseases, the Ministry of Health and Welfare of Japan*. 1989; 13-4 (in Japanese).
5. Shima S, Shikano T, Kitamura T, Asai M. New self-rating scales for depression. *J Clin Psych* 1985; 27: 717-23 (in Japanese).
6. Agari I. *Handbook of psychological assessment*. Tokyo: Nishimura Shoten; 1993 (in Japanese).
7. Horie Y. A Japanese version of the Health Locus of Control Scales. *Jpn J Health Psychol* 1991; 27: 1-7 (in Japanese).