Clinical study

Affective improvement of neurological disease patients and caregivers using an automated telephone call service

Yasuyuki Ohta [a], Toru Yamashita [a], Nozomi Hishikawa [a], Kota Sato [a], Noriko Hatanaka [a], Mami Takemoto [a], Shinji Doutare [b], Koji Abe [a,*]

[a] Department of Neurology, Graduate School of Medicine, Dentistry and Pharmaceutical Sciences, Okayama University, 2-5-1 Shikata-cho, Okayama 700-8558, Japan
[b] Doutare Medical Clinic, 1-20-3 Tokiwadaira, Matsudo 270-2261, Japan

ARTICLE INFO

ABSTRACT

Neurological disease patients living alone or with a single caregiver need a support system to care for their psychological symptoms. We evaluated the clinical effects of a unique telephone call system that automatically called participants at their desired times once a week for 3 months. In total, 104 neurological disease patients and caregivers were evaluated by the geriatric depression scale, apathy scale and state and trait anxiety inventories (STAI) forms X-I for depression, apathy and state anxiety, respectively. High baseline STAI scores (40≥) significantly improved in the Parkinson's disease (PD), amyotrophic lateral sclerosis (ALS), and spinocerebellar degeneration (SCD) + multiple system atrophy (MSA) patients (p = 0.001, p = 0.013 and p = 0.046, respectively) after patients/caregivers used the telephone call service. The baseline (pre) STAI score significantly correlated with the score change (post-pre) in PD, ALS, SCD + MSA, Alzheimer' s disease patients (ADp), and caregivers for ADp (p < 0.0001, p = 0.001, p = 0.011, p = 0.025 and p = 0.020, respectively). The geriatric depression scale and apathy scale did not significantly improve. The present study suggests that there is a positive effect of using an automated telephone call service for anxiety in neurological disease patients and caregivers, especially in ALS, SCD + MSA and PD patients with high STAI scores (40≥).

1. Introduction

Patients with a chronic progressive neurological disease, such as amyotrophic lateral sclerosis (ALS), spinocerebellar degeneration (SCD), multiple system atrophy (MSA), Parkinson's disease (PD), multiple sclerosis (MS) or Alzheimer's disease (ADp), and caregivers for AD patients (ADc) are at risk for psychological symptoms including anxiety, depression and apathy [1–3]. We previously reported an anxiety change after genetic testing for presymptomatic hereditary SCD patients [4]. Psychological symptoms affect disease symptoms and decrease the quality of life, but effective treatments and care have not been fully investigated in ALS, SCD + MSA, PD, MS, ADp and ADc. In particular, neurological disease patients living alone or with a single caregiver at home need a support system to help care for their psychological symptoms.

In the present study, therefore, we used a unique telephone call system for neurological disease patients living alone or with a single caregiver. This system automatically called participants at their desired time once a week, and participants could answer questions simply by pressing the numbers #1, #2 or #3. We evaluated the clinical effects of the telephone call service for psychological symptoms, such as anxiety, depression or apathy, of patients and caregivers.

2. Methods

2.1. Participants

The present study included volunteer participants living alone (n = 15) or with a single caregiver (n = 89), with ALS (n = 19), SCD (n = 11), MSA (n = 7), PD (n = 27), MS (n = 16) or ADp (n = 13), or a caregiver for ADp (ADc) (n = 11) from an outpatient clinic at Okayama University Hospital. The ALS, MSA, PD, MS and ADp cases were diagnosed by expert neurological clinicians according to the revised El Escorial criteria (possible, probable or definite) [5], MSA criteria [6,7], U.K. Parkinson's Disease Society Brain Bank clinical criteria [8], revised McDonald criteria [9], the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition or the International Classification of Diseases, Tenth Revision, respectively. SCD cases included two spinocerebellar ataxia (SCA) 2, one SCA1, one SCA3, one SCA31, one cortical cerebellar atrophy and five

* Corresponding author.
  E-mail address: yasuyuki@okayama-u.ac.jp (K. Abe).

others, diagnosed by expert neurological clinicians and DNA analysis. Eleven SCD and seven MSA cases are combined in the present study. All participants gave written informed consent and the Okayama University Ethics Review Board approved all study procedures (approval # 2196).

2.2. Automated telephone call service and clinical evaluation

All participants received an automated telephone call service (Andes phone®) to check their medical conditions at their desired times, once a week for 3 months. The participants (patients or caregivers) answered questions from the telephone service by pressing the appropriate number: #1 for 'no problem', #2 for 'request a phone call within a few days by a medical consultant', and #3 for 'request an immediate phone call by a medical consultant'. When the participants pressed #2 or #3 for the telephone service, a member of the Okayama Prefecture Intractable Disease Medical Council staff called them back within a few days (for #2) or as soon as possible (for #3) to listen to the problems from the patients or caregivers and carefully advise them of necessary medical consultations. The percentage of each answer type (#1, #2, and #3), and any calls/answers made in error, by the participants was recorded.

Just before (pre) and 3 months after (post) the telephone call service, all participants were evaluated at the outpatient clinic of Okayama University Hospital by affective assessments such as the geriatric depression scale (GDS) [10], apathy scale (AS) [11] and state and trait anxiety inventories (STAI) [12] forms X-I for depression, apathy and state anxiety, respectively. They were also evaluated by the general cognitive test mini-mental state examination (MMSE) [13] at the outpatient clinic. Clinical demographic data such as age, sex and disease duration were also analyzed.

2.3. Statistical analysis

Comparisons between baseline characteristics (gender, age and disease duration), the scores of cognitive (MMSE) and affective assessments before (pre) and after (post) the telephone call service, and the percentage of answer types (no problem, request a call back within a few days or request an immediate call back, or any calls/answers made in error) for the telephone service for six groups (ALS, SCD + MSA, PD, MS, ADp, and ADc) were carried out with the Kruskal–Wallis test for continuous variables, and with Pearson's chi-squared test (χ^2) for comparison of proportions. Changes in affective assessment scores between pre- and post-telephone service were analyzed using the Wilcoxon signed-rank test. Spearman's rank correlation-coefficient test was conducted to examine correlations among STAI scores of pre-telephone service and subtraction (post- from pre-telephone service), and among STAI scores of subtraction and the percentage of 'request call back' answers for the telephone service. Statistical analyses were performed using GraphPad Prism 5 (version 5.00; GraphPad Software, Inc., San Diego, CA). A P value of less than 0.05 was considered significant.

3. Results

3.1. Clinical characteristics of neurological disease patients and caregivers

The clinical characteristics of ALS, SCD plus MSA, PD, MS, ADp and ADc are shown in Table 1. The ratio of men was larger in ALS patients, while it was smaller in MS, ADp and ADc groups (χ^2=16.37; p = 0.006). The mean ages at examination of MS patients were younger than in the other five groups ($^{###}$p < 0.001 vs ALS, ¶p < 0.05 vs SCD + MSA, $^{!!!}$p < 0.001 vs PD, $^{$$$}$p < 0.001 vs ADp and ADc), while the ages of ADp patients were older compared with SCD + MSA patients (¶p < 0.05), and the disease durations of ADp patients were shorter compared with SCD + MSA, PD and MS patients (¶p < 0.05 vs SCD + MSA, $^{!!}$p < 0.01 vs PD, $^{$}$p < 0.05 vs MS). For general cognitive assessments, MMSE scores were significantly lower in ADp patients compared with ALS, PD and MS patients (Table 1, $^{#}$p < 0.05 vs ALS, $^{!!}$p < 0.01 vs PD, $^{$$$}$p < 0.001 vs MS).

3.2. Effects of the automated telephone call service

Baseline GDS scores were not different among all six groups before the automated telephone call service (Table 1). Although

Table 1
Clinical characteristics of patients with ALS, SCD + MSA, PD, MS, AD and caregivers for AD.

	ALS	SCD + MSA	PD	MS	ADp	ADc	Statistical Analysis
No. of cases	19	18	27	16	13	11	
Men (%)	68.4	50.0	48.1	18.8	7.7	36.4	$^{a}\chi2 = 16.37$; p = 0.006
Age at examination (y)	67.3 ± 9.0	63.6 ± 12.3	71.7 ± 6.8	37.7 ± 9.3$^{###,¶,!!!}$	76.3 ± 4.3¶,$$}$	75.7 ± 6.3 $^{$$$}$	^{b}p<0.0001
Disease duration (y)	3.5 ± 3.1	7.6 ± 5.9	6.3 ± 4.5	6.4 ± 5.4	2.1 ± 1.5$^{¶,!!,$}$		^{b}p = 0.0007
MMSE	27.3 ± 3.0	27.2 ± 2.7	27.7 ± 2.0	28.8 ± 1.6	23.9 ± 2.9$^{#,!!,$$$}$		^{b}p = 0.001
Pre-telephone service							
GDS	6.7 ± 3.3	6.2 ± 4.3	5.2 ± 3.7	5.7 ± 3.8	4.1 ± 4.1	3.6 ± 3.4	^{b}p = 0.179
AS	17.1 ± 6.0	18.0 ± 10.9	12.9 ± 7.4	14.7 ± 7.9	10.5 ± 9.4	13.5 ± 10.9	^{b}p = 0.074
STAI (X-I)	44.4 ± 12.2	44.0 ± 14.1	42.0 ± 12.5	37.9 ± 15.6	33.4 ± 9.4	34.9 ± 8.2	^{b}p = 0.068
Post-telephone service							
GDS	6.7 ± 4.1	5.9 ± 3.7	4.9 ± 3.8	5.2 ± 3.8	2.3 ± 2.2$^{#}$	4.9 ± 4.4	^{b}p = 0.048
AS	17.4 ± 8.6	17.3 ± 9.0	12.6 ± 6.8	12.3 ± 7.4	13.8 ± 9.1	15.7 ± 8.9	^{b}p = 0.336
STAI (X-I)	38.5 ± 10.3	39.2 ± 11.3	32.2 ± 9.6	39.2 ± 13.8	34.0 ± 10.5	34.4 ± 7.2	^{b}p = 0.199
Answer for telephone service							
No problem (%)	78.6	76.3	68.5	73.9	82.3	65.9	^{b}p = 0.204
Request call back (%)	3.5	4.5	10.0	1.1	0.7	3.8	^{b}p = 0.092
Error (%)	17.9	19.2	21.5	25.0	17.0	30.3	^{b}p = 0.381

Data are expressed mean ± SD. Intergroup comparisons: $^{#}$p < 0.05 vs ALS; $^{###}$p < 0.001 vs ALS; ¶p < 0.05 vs SCD + MSA; ¶¶p < 0.01 vs SCD + MSA; $^{!!}$p < 0.01 vs PD; $^{!!!}$p < 0.001 vs PD; $^{$}$p < 0.05 vs MS $^{$$$}$p < 0.001 vs MS.
ADc, Alzheimer's disease-caregiver; ADp, Alzheimer's disease-patient; ALS, amyotrophic lateral sclerosis; AS, apathy score; GDS, geriatric depression scale; MMSE, mini-mental state examination; MS, multiple sclerosis; MSA, multiple system atrophy; PD, Parkinson disease; SCD, spinocerebeller degeneration; SD, standard deviation; STAI, state-trait anxiety inventory.
^{a} Chi square test.
^{b} Kruskal-Wallis test.

GDS scores did not significantly change after the telephone call service in all six groups (Fig. 1, top), the GDS score of ADp patients (2.3 ± 2.2) was significantly better compared with ALS patients (6.7 ± 4.1) after the telephone call service (Table 1, #p < 0.05).

Baseline AS scores showed worse tendencies in SCD + MSA and ALS (18.0 ± 10.9 and 17.1 ± 6.0, respectively) than the other four groups before the telephone call service, but they were not significant (Table 1, p = 0.074). AS scores did not significantly change after the telephone call service in all six groups (Fig. 1, middle).

Baseline STAI scores (forms X-I) showed worse tendencies in the ALS, SCD + MSA and PD groups (44.4 ± 12.2, 44.0 ± 14.1 and 42.0 ± 12.5, respectively) than the other three groups before the telephone call service, but they were not significant (Table 1, p = 0.068). However, such tendencies disappeared after the telephone call service because of the significant improvements in the ALS, SCD + MSA, and PD groups (Table 1, Fig. 1, bottom). STAI scores of the ALS and SCD + MSA groups improved after the telephone call service (38.5 ± 10.3, p = 0.122 and 39.2 ± 11.3, p = 0.157, respectively), and the PD group significantly improved (32.2 ± 9.6, **p = 0.005) (Table 1, Fig. 1, bottom).
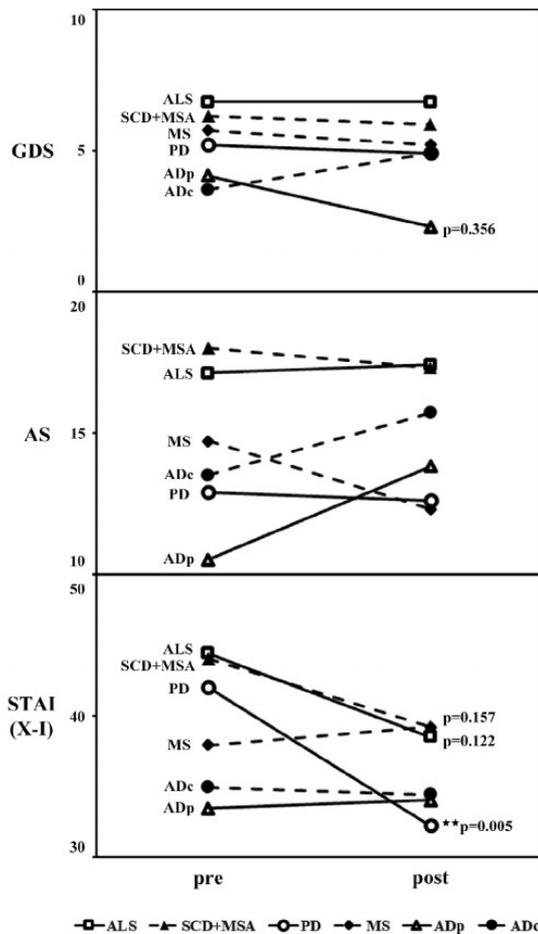

Fig. 1. Affective assessments (GDS, AS, and STAI X-I) of ALS, SCD + MSA, PD, MS, ADp, and ADc before (pre) and after (post) telephone call service. Unlike GDS and AS, STAI scores greatly improved in ALS, SCD + MSA and PD groups after telephone call service. **p < 0.01.

Comparison between baseline (pre) STAI score and the score change from pre to post (post-pre) showed significant correlations in the ALS, SCD + MSA, PD, ADp and ADc groups (Fig. 2, ***p = 0.001, *p = 0.011, ****p < 0.0001, *p = 0.025 and *p = 0.020, respectively). Further analysis for the selected subjects with high STAI scores (40≥) confirmed the STAI improvement after the telephone call service in PD (n = 13, 48.2% of total PD cases), ALS (n = 12, 63.2% of total ALS cases) and SCD + MSA (n = 11, 61.1% of total SCD + MSA cases) patients (***p = 0.001, *p = 0.013 and *p = 0.046, respectively), but not in MS (n = 5, 31.3% of total MS cases), ADp (n = 3, 23.1% of total ADp cases) or ADc (n = 3, 27.3% of total ADc cases) group (Fig. 3).

Answers for the telephone call service for #2 or #3 showed a higher tendency only in PD patients (10.0%) and not in the other five groups, but it was not significant (Table 1, p = 0.092). However, the answers for 'no problem or 'an error' were similar in all six groups (Table 1, bottom). The high rate of answer (3.5–7.7% request/3M) in MS patients (n = 3) requesting a call back was significantly correlated to the improvement of STAI scores after the telephone call service (****p < 0.0001), but not in the ALS, SCD + MSA, PD, ADp or ADc groups (date not shown).

4. Discussion

The present study investigated the clinical effects of an automated telephone call service for depression, apathy and state anxiety in neurological disease patients (ALS, SCD + MSA, PD, MS, and ADp) living alone or with a single caregiver (ADc). STAI scores (state anxiety) greatly improved in only PD group (Fig. 1, **p = 0.005) after 3 months of using the telephone call service. However, the baseline (pre) STAI score significantly correlated with the score change (post-pre) in the ALS, SCD + MSA, PD, ADp and ADc groups (Fig. 2, ***p = 0.001, *p = 0.011, ****p < 0.0001, *p = 0.025 and *p = 0.020, respectively), suggesting the higher baseline STAI scores of participants the better the improvement after using the telephone call service (Fig. 2). Furthermore, high baseline STAI scores (40≥) of the PD, ALS and SCD + MSA groups significantly improved after telephone call service (Fig. 3, ***p = 0.001, *p = 0.013 and *p = 0.046, respectively). While the GDS (depression) and AS (apathy) did not improve significantly.

Anxiety is an important psychological symptom in ALS [14], SCD + MSA [15], PD [3,16], MS [17,18], ADp [19] and ADc [2,20]. Although anxiety is generally related to disease severity in PD [16] and female sex, limited social supports and psychosocial pressures in MS [17,18], effective treatments and care for anxiety have not been fully investigated in ALS, SCD + MSA, PD, MS and ADp. Previous reports showed that telephone support systems were effective for anxiety in PD [3] and ADc [2], but patients and caregivers had to call by themselves in the previous telephone systems. In contrast, the present telephone call service (Andes phone®) was a unique automated support system that called participants at their desired times once a week, and participants could answer simply by pressing the numbers #1, #2 or #3. Doctors could check the status of the patients every week, and the patients with high anxiety were able to reduce their anxiety levels at home (Figs. 2 and 3). A previous report showed that frequent telephone calls from PD patients to hospitals were related to the anxiety of the patients [21], and PD patients showed a higher tendency (10.0%) of 'request a call back' answers for the telephone call service than the other five groups in the present study (Table 1). However, a high request for a call back was not correlated to the improvement of STAI scores in ALS, SCD + MSA, PD, ADp or ADc groups (date not shown). This result suggested that the anxiety levels of the participants improved simply by receiving the automated call service every week at home.
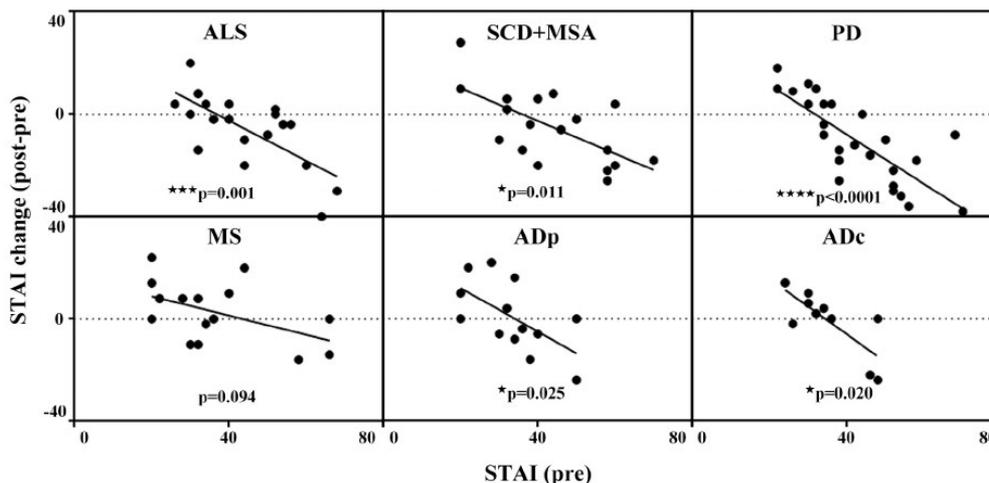
77

Fig. 2. Scatter plots for relationships between baseline (pre) STAI and STAI score change (post-pre) in ALS, SCD + MSA, PD, MS, ADp, and ADc. The baseline STAI scores significantly correlated with the post-pre STAI scores in ALS, SCD + MSA, PD, ADp and ADc. *p < 0.05, ***p < 0.001, ****p < 0.0001.
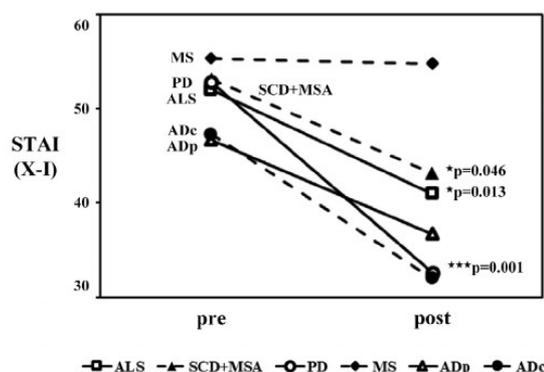

Fig. 3. Changes of STAI scores of ALS, SCD + MSA, PD, MS, ADp, and ADc who were high baseline STAI scores (40≥). High baseline STAI scores of PD, ALS and SCD + MSA groups significantly improved after telephone call service. *p < 0.05, ***p < 0.001.

The present study showed that the higher baseline STAI scores of participants improved better after using the telephone call service (Fig. 2), but the percentage of participants with high baseline STAI scores (40≥) were small in all group, especially in MS, ADp and ADc groups (PD 48.2%, ALS 63.2%, SCD + MSA 61.1%, MS 31.3%, ADp 23.1%, and ADc 27.3%). That could be the reason that only PD group, and PD, ALS and SCD + MSA groups with high baseline STAI scores showed the significant improvement of STAI scores (Figs. 1 and 3). To confirm the efficacy of the telephone call service, more numbers of participants should be investigated in future. For MS patients, increasing numbers of patients requesting a call back might induce the significant improvement of anxiety in the present telephone call service, because the high rate of answer in MS patients (n = 3) requesting a call back was significantly correlated to the improvement of STAI scores.

In conclusion, the present study showed the positive effect of an automated telephone call service for anxiety in neurological disease patients (ALS, SCD + MSA, PD, MS, and ADp) and their caregivers (ADc), especially in ALS, SCD + MSA and PD patients with high STAI scores (40≥) (Figs. 1–3). The present automated telephone call service could be a useful care tool for neurological disease patients living alone or with a single caregiver.

Conflict of interest

Nothing to report.

References

[1] Abe K, Yamashita T, Hishikawa N, Ohta Y, Deguchi K, Sato K, et al. A new simple score (ABS) for assessing behavioral and psychological symptoms of dementia. J Neurol Sci 2015;350:14–7.
[2] Mahoney DF, Tarlow BJ, Jones RN. Effects of an automated telephone support system on caregiver burden and anxiety: findings from the REACH for TLC intervention study. Gerontologist 2003;43:556–67.
[3] Veazey C, Cook KF, Stanley M, Lai EC, Kunik ME. Telephone-administered cognitive behavioral therapy: a case study of anxiety and depression in Parkinson's disease. J Clin Psychol Med Sett 2009;16:243–53.
[4] Abe K, Itoyama Y. Psychological consequences of genetic testing for spinocerebellar ataxia in the Japanese. Eur J Neurol 1997;4:593–600.
[5] Brooks BR, Miller RG, Swash M, Munsat TL, World Federation of Neurology Research Group on Motor Neuron D. El Escorial revisited: revised criteria for the diagnosis of amyotrophic lateral sclerosis. Amyotroph Lateral Scler Other Motor Neuron Disord 2000;1:293–9.
[6] Fanciulli A, Wenning GK. Multiple-system atrophy. N Engl J Med 2015;372:1375–6.
[7] Gilman S, Low PA, Quinn N, Albanese A, Ben-Shlomo Y, Fowler CJ, et al. Consensus statement on the diagnosis of multiple system atrophy. J Neurol Sci 1999;163:94–8.
[8] Hughes AJ, Daniel SE, Lees AJ. Improved accuracy of clinical diagnosis of Lewy body Parkinson's disease. Neurology 2001;57:1497–9.

[9] Polman CH, Reingold SC, Banwell B, Clanet M, Cohen JA, Filippi M, et al. Diagnostic criteria for multiple sclerosis: 2010 revisions to the McDonald criteria. Ann Neurol 2011;69:292–302.

[10] Lesher EL, Berryhill JS. Validation of the geriatric depression scale-short form among inpatients. J Clin Psychol 1994;50:256–60.

[11] Starkstein SE, Fedoroff JP, Price TR, Leiguarda R, Robinson RG. Apathy following cerebrovascular lesions. Stroke 1993;24:1625–30.

[12] Gaudry E, Vagg P, Spielberger CD. Validation of the state-trait distinction in anxiety research. Multivariate Behav Res 1975;10:331–41.

[13] Folstein MF, Folstein SE, McHugh PR. "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. J Psychiatr Res 1975;12:189–98.

[14] Kurt A, Nijboer F, Matuz T, Kubler A. Depression and anxiety in individuals with amyotrophic lateral sclerosis: epidemiology and management. CNS Drugs 2007;21:279–91.

[15] Kawai Y, Suenaga M, Watanabe H, Sobue G. Cognitive impairment in spinocerebellar degeneration. Eur Neurol 2009;61:257–68.

[16] Dissanayaka NN, Sellbach A, Matheson S, O'Sullivan JD, Silburn PA, Byrne GJ, et al. Anxiety disorders in Parkinson's disease: prevalence and risk factors. Mov Disord. 2010;25:838–45.

[17] Zorzon M, de Masi R, Nasuelli D, Ukmar M, Mucelli RP, Cazzato G, et al. Depression and anxiety in multiple sclerosis. A clinical and MRI study in 95 subjects. J Neurol 2001;248:416–21.

[18] Korostil M, Feinstein A. Anxiety disorders and their clinical correlates in multiple sclerosis patients. Mult Scler 2007;13:67–72.

[19] Teri L, Ferretti LE, Gibbons LE, Logsdon RG, McCurry SM, Kukull WA, et al. Anxiety of Alzheimer's disease: prevalence, and comorbidity. J Gerontol A Biol Sci Med Sci 1999;54:M348–52.

[20] Mahoney R, Regan C, Katona C, Livingston G. Anxiety and depression in family caregivers of people with Alzheimer disease: the LASER-AD study. Am J Geriatr Psychiatry 2005;13:795–801.

[21] Liu AA, Boxhorn CE, Klufas MA, Christos PJ, Thorne JT, Shih AY, et al. Clinical predictors of frequent patient telephone calls in Parkinson's disease. Parkinsonism Relat Disord 2011;17:95–9.