

The Validity and Reliability of a Screening Questionnaire for Parkinson's Disease in a Community

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Objectives: Parkinson's disease is one of the most common neurodegenerative diseases in the elderly population. In order to estimate the prevalence of Parkinson's disease in the community, the application of a good screening tool is essential. We evaluated the validity and reliability of a Parkinson's disease screening questionnaire and propose an alternative measure to improve its validity for use in community surveys.

Methods: We designed the study in a three-phase approach consisting of a screening questionnaire, neurologic examination, and confirmatory examination. A repeated survey was administered to patients with disease detected in the community and on 150 subjects. We examined internal consistency using Cronbach's alpha test, test-retest reliability using the kappa statistic, and validity using sensitivity, specificity, and ROC curves. Unadjusted odds ratios were utilized for the estimation of weights for each questionnaire item.

Results: The Cronbach's alpha of the questionnaire was 0.708. The kappa statistic for test-retest reliability was good to generally fair in most of the items. When newly proposed weighting scores were used, the optimum cut-off value was 7/8. When cut-off value was 5/6 for surveying prevalence in a community, the sensitivity was 0.98, and the specificity was 0.61, with simultaneous improvement in reliability.

Conclusions: We recommend 5/6 as the ideal cut-off value for the survey of PD prevalence in community. This questionnaire designed for the Korean community could help future epidemiologic studies of PD.

Key words: Screening, Questionnaire, Validity, Reliability, Parkinson's disease, Community
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INTRODUCTION

Parkinson's disease (PD) is one of the most common neurodegenerative disorders in the elderly throughout the world. It is characterized by prominent motor deteriorations, including tremor, rigidity, and bradykinesia, which develop from progressive degeneration of dopaminergic neurons in the substantia nigra [1,2]. In contrast to other neurodegenerative disorders, early detection and management of PD has a positive impact on quality of life and prolong survival. Therefore, in terms of public health, both to detect patients in an early phase of disease as well as to monitor the prevalence of PD in the community are important.

The prevalence of PD in a community, which is generally variable according to genetic, environmental, and population background, ranges from 100 to 300 per

100,000 [3-5]. Across different geographic regions, great variance in the reported prevalence of PD has been reported. Actual prevalence is also highly dependent on survey methods. In general, door-to-door surveys detect a higher number of cases in a community, as compared to surveys using health records or a registry, which produces an underestimation of the cases actually present in the community [6,7]. In Korea, reports on the prevalence of PD are very rare. Only one community survey has been done, and it was performed on an urban population near the capital area, estimating a prevalence of 1,473/100,000 in the elderly population [8]. This prevalence is higher, as compared to both reports from neighboring countries and the previous estimation of treatment prevalence based on the National Health Insurance database [9]. An incidence from 2.36 to 2.68/100,000/year has been reported in a cohort of workers at a shipbuilding company [10], but this finding

is also based on the medical records for an adult male population.

For door-to-door surveys, a good screening tool for detecting PD-specific movement symptoms is critical. Several screening tools have been developed for community surveys of PD [11-13]. One, reported by Duarte et al. [12], is used for both hospital- and community-based screening surveys for PD, and the nine-item questionnaire used in that study can be easily applied to both clinical and community settings. Despite the reportedly high sensitivity and specificity, however, validation in the community setting has not yet been achieved. Therefore, a tool that can be used for PD screening in a community survey is needed.

The objectives of this study are to evaluate the validity and reliability of a PD screening tool in a community survey and to develop new criteria for PD screening based on the determined validity.

METHODS

I. Subjects

Gangneung city, Gangwon Province is located on the eastern coast of Korea and is a mixed urban and rural area. The city had a population of 224,391 in the 2006 census, and there is a population of 24,103 people over 65 years of age. Among the population, 55,168 (24.3%) live in rural areas including eight basic administrative districts (one eup and seven myeons) and 169,223 (75.7%) live in urban areas including 13 basic administrative districts, dongs. We sampled ten percent of the elderly population in each area with multistage cluster sampling to reflect the distributions of rural and urban populations with over 65 years of age in the city. First, we sampled eight basic administrative districts (one eup, two myeons and five dongs) among the whole urban and rural areas after considering of characteristics in industrial structures and dwelling sites. Second, we random sampled the smallest administrative districts (ri in eup or myeon districts and tong in dong districts) among the selected eight basic administrative districts. All of the people equal to or older than 65 years in the sampled administrative districts were surveyed by interviewers. The total number of subjects was 2,238. Among those, people who were absent for a long-term

period (187 persons), those who were not actual residents of the area (342 persons), and those who refused to enroll in the study (198 persons) were excluded, leaving 1,511 study subjects. Long-term absentees were defined as persons who were out of contact during five or more interviewer visits.

Among the 1,511 persons surveyed, 1,506 (608 men and 898 women) completed the questionnaire. Some items of questionnaire could not be surveyed in some elderly people because of their illiteracy. To assess test-retest reliability of the screening tool, we selected 26 of 42 PD patients in addition to selecting randomly 150 participants among 1,464 non-PD subjects. Among the 42 PD patients, 16 living in a nursing home were excluded due to communication problems, immobility, or severe cognitive impairment. Surveys were administered from June 21 to November 3, 2007. Informed consent was obtained from all participants after an explanation was given about the study. This study was acknowledged by the Institutional Review Board of Samsung Medical Center (2007-05-001).

II. Study Design

Our study was designed as a three-phase approach to identify PD patients in the community. The first phase was the administration of a door-to-door survey by trained interviewers using a screening tool. We trained 34 senior students in the Department of Nursing to administer the PD screening questionnaire, to select cases for the second phase evaluation, and to interview the subjects. A screening questionnaire was given to the participants, and interviewers conducted the surveys face-to-face.

The second phase was a clinical examination by a neurologist. Participants who screened positive in the questionnaire or were suspected based on the interviewers' judgment according to criteria for PD diagnosis (regardless of scores) were examined to confirm PD. The criteria for the second phase examination were 1) a screening questionnaire score sum of 42 or more, 2) having a past history of PD or taking medicine for PD treatment, or 3) at least one or more of the following: resting tremor, bradykinesia, or rigidity regardless of score level. We examined the subjects selected for the second phase at a branch of public health center or in their houses if they were

Table 1. General characteristics of the study subjects

	Total subjects (n=1,506)	Control group [A] (n=1,464)	Case group [B] (n=42)	Significance* [A vs. B]
Gender				
Male	608 (40.4%)	599 (40.9%)	9 (21.4%)	0.011
Female	898 (59.6%)	865 (59.1%)	33 (78.6%)	
Age (yr)				
60 - 64	39 (2.6%)	39 (2.7%)	0 (0.0%)	<0.001
65 - 74	875 (58.1%)	863 (58.9%)	12 (28.6%)	
75 - 84	466 (30.9%)	445 (30.4%)	21 (50.0%)	
≥ 85	126 (8.4%)	117 (8.0%)	9 (21.4%)	
mean ± SD	73.9 ± 6.8	73.8 ± 6.8	78.2 ± 6.7	
Residence				
Rural area	688 (45.7%)	657 (44.9%)	15 (35.7%)	<0.001
Urban area	818 (54.3%)	807 (55.1%)	11 (26.2%)	
Nursing institution			16 (38.1%)	
Education level				
None	524 (35.1%)	500 (34.4%)	24 (57.1%)	0.007
Elementary school	585 (39.2%)	572 (39.2%)	13 (31.0%)	
Middle school	132 (8.8%)	132 (9.1%)	0 (0.0%)	
High school or more	253 (16.9%)	249 (17.1%)	4 (9.5%)	

* Comparison between total subjects [A] and case group [B] by Chi-square test

unable to visit their branch of public health center.

The third phase was performed at a university hospital in the study area in order to confirm and subtype the diagnosis and to exclude other diseases with laboratory and imaging studies. We excluded cases of secondary parkinsonism and Parkinson-plus syndrome from the study.

Repeated secondary interviews to evaluate test-retest reliability using the same screening questionnaire were conducted by the same trained interviewer. However, the secondary examinations for PD patients were conducted at the time of the second phase examination by a trained nurse. The typical period between test and retest was between one to two weeks in PD patients group and about three months in control group.

III. Screening Tool

The contents of the questionnaire for screening for PD included demographic characteristics, a motor function questionnaire, and an evaluation of cognitive function and activities of daily living. The motor function questionnaire used in this survey was developed by Tanner et al. [11] and modified by Duarte et al. [12]. It was chosen because of its high sensitivity and specificity. It consisted of nine questions with the possible responses "yes," "no," and "uncertain." These questions were translated into Korean (Appendix). The total score for motor function was calculated from a weighted total score according to Duarte's criteria.

Cognitive function was examined by the Korean version of the Mini-Mental State Examination (MMSE-KC) [14]. For the screening for dementia, we used the 15-item Korea Dementia Screening Questionnaire (KDSQ) [15].

IV. Statistical Analyses

We considered "uncertain" answers to be negative answers. For the internal consistency analysis, we calculated the Cronbach's alpha for the screening questionnaire. Test-retest reliabilities between the first and the second questionnaires for each item were calculated using kappa statistics. The proportion of positive answers to each question was calculated both in the test cases and in the normal subjects. Odds ratios could be expressed as the proportion of positive answers among the case group divided by the proportion of positive answers among the control group. Odds ratios were calculated and used to weight each item after rounding off to the nearest integer. The total score for the screening questionnaire was calculated using both the original scoring methods proposed by Duarte et al. [12] and by new weighting schemes developed by the authors. Test-retest reliability was calculated using the kappa statistic for each cut-off value once the weighting scores were adopted.

The sensitivity, specificity, and positive predictive value of the screening questionnaire were calculated using both scoring methods. New cut-off values to

Table 2. Internal consistency of the screening questionnaire

(N=1,506)

Question	Significance of Cronbach's alpha if the question was deleted
1. Do you have trouble arising from a chair?	0.675
2. Is your hand writing smaller than it once was?	0.675
3. Do people tell you that your voice is softer than it once was?	0.686
4. Is yours balance, when walking, poor?	0.658
5. Do you feet suddenly seem to freeze in door-ways?	0.674
6. Does your face seem less expressive than it used to?	0.693
7. Do your arms and legs shake?	0.704
8. Do you have trouble buttoning buttons?	0.683
9. Do you shuffle yours feet and take tiny steps when you walk?	0.670
Total Cronbach's alpha	0.708

distinguish suspected subjects from normal subjects were investigated with receiver-operator-characteristic (ROC) curve analysis and by proportion of the area under the curve. Cut-off point, which sum of the sensitivity and specificity were maximized, was selected as optimum cut-off value. When sensitivity was equal or more than 0.95, cut-off point with the maximum of specificity was selected as ideal cut-off value for survey of PD prevalence in a community. When specificity was more than 0.95, cut-off point with the maximum of sensitivity was selected as initial screening tool in hospital examination. Data analysis was performed using SPSS

version 12.0 (SPSS Inc., Chicago, IL, USA).

RESULTS

I. Demographics

Among a total of 1,506 subjects, there were 608 males and 898 females (Table 1). The mean age was 73.9 ± 6.8 years, with the range of 65~74 years constituting 58.1% of the total study population. Although we sampled subjects who were 65 years or older by legal data, 39

Table 3. Test-retest reliability of the screening questionnaire

Question	Retest control group (n=150)		Case group (n=26)	
	Agreement* (%)	Kappa (\pm S.E.)	Agreement (%)	Kappa (\pm S.E.)
1. Do you have trouble arising from a chair?	72.7	0.44 \pm 0.07	76.0	0.41 \pm 0.20
2. Is your hand writing smaller than it once was?	72.7	0.06 \pm 0.09	53.8	0.24 \pm 0.15
3. Do people tell you that your voice is softer than it once was?	81.8	0.36 \pm 0.10	60.0	0.27 \pm 0.15
4. Is yours balance, when walking, poor?	73.3	0.42 \pm 0.08	68.0	0.26 \pm 0.17
5. Do you feet suddenly seem to freeze in door-ways?	81.3	0.33 \pm 0.10	60.0	0.25 \pm 0.15
6. Does your face seem less expressive than it used to?	77.6	0.30 \pm 0.09	77.3	0.55 \pm 0.17
7. Do your arms and legs shake?	85.0	0.07 \pm 0.10	72.0	0.39 \pm 0.19
8. Do you have trouble buttoning buttons?	92.0	0.36 \pm 0.14	80.0	0.60 \pm 0.16
9. Do you shuffle yours feet and take tiny steps when you walk?	83.3	0.20 \pm 0.11	64.0	0.26 \pm 0.16

* Agreement (%) means the proportion of same answer in each test and retest question

Table 4. Weighting of specific screening questions

(N=1,506)

Question	Case group			Control group			A/B	Reference [†] weighting scores	Proposed weighting scores
	Total answers	Positive answers	Proportion (A)	Total answers	Positive answers	Proportion (B)			
1	42	35	0.83	1,464	709	0.48	1.72	6	2
2	33*	14	0.42	1,312	153	0.12	3.64	7	4
3	42	18	0.43	1,464	285	0.19	2.20	8	2
4	42	32	0.76	1,464	564	0.39	1.98	9	2
5	42	26	0.62	1,464	233	0.16	3.89	6	4
6	42	21	0.50	1,464	267	0.18	2.74	6	3
7	42	28	0.67	1,464	212	0.14	4.60	9	5
8	42	22	0.52	1,464	134	0.09	5.72	8	6
9	42	21	0.50	1,464	237	0.16	3.09	8	3

* Some subjects could not answer due to illiteracy

[†] These weighting scores were developed by Duarte's study

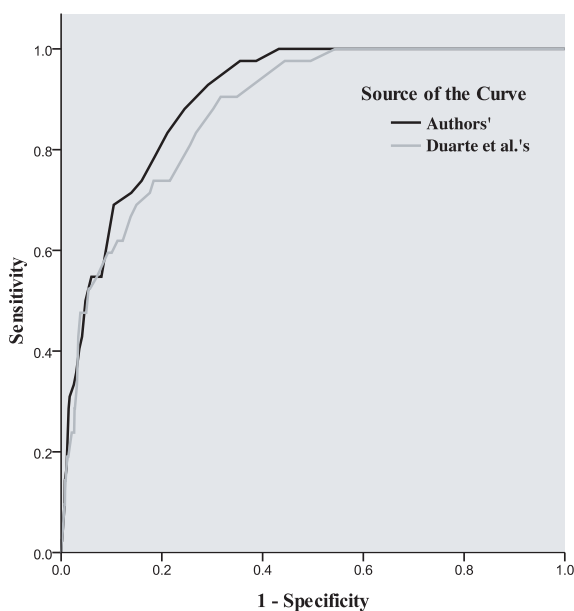


Figure 1. ROC curve when adopting weighting scores in each study.

The area under the curve of the ROC curve when adopting Duarte's weighting scores was 0.877 (95% CI=0.835-0.920), when adopting the authors' weighting scores it was 0.902 (95% CI=0.868-0.935).

ROC: receiver-operator-characteristic, CI: confidence interval

subjects under 65 years old were surveyed due to differences in legal registrations of birth dates and actual birth dates. Among all of the subjects, 688 (45.7%) lived in rural areas. In terms of education level, 35.1% of subjects were uneducated, and approximately 65% of subjects had at least an elementary school education. Among 42 Confirmed PD patients, 20 patients were screened by a questionnaire criteria, 22 patients S.E. were screened by judgment of interviewers in the first phase.

II. Reliability of the Screening Questionnaire

The total Cronbach's alpha for internal consistency of the questionnaire was 0.708 (Table 2). Under conditions in which each question was individually deleted, Cronbach's alpha showed a similar distribution.

The test-retest reliability of the questionnaire was assessed using the kappa index. Among the 176 subjects who participated, the kappa for each item ranged from 0.24 to 0.60 in the case group and from 0.06 to 0.44 in the retest control group (Table 3). Some subjects may have had difficulty understanding question 2 ("Is your hand writing smaller than it once was?"). There was

Table 5. Validity of the screening questionnaire

(N=1,506)

Cut-off value of the screening questionnaire	Sensi- tivity	Speci- ficity	PPV	AUC (95% C.I.)
Adoption of reference weighting scores 41/42	0.48	0.95	0.23	0.877 (0.835-0.920)
Adoption of proposed weighting scores*				0.902 (0.868-0.935)
5/6	0.98	0.61	0.07	
7/8	0.93	0.71	0.08	
17/18	0.50	0.95	0.23	

PPV: positive predictive value

AUC: area under the curve, CI: confidence interval

* Maximum score is 31 when proposed weighting scores is adopted

Table 6. Validity of the screening questionnaire in retest

(N=176)

Cut-off value of the screening questionnaire	Sensi- tivity	Speci- ficity	PPV	AUC (95% C.I.)
Adoption of reference weighting scores 41/42	0.69	0.91	0.58	0.906 (0.836-0.976)
Adoption of proposed weighting scores*				0.908 (0.841-0.975)
5/6	0.96	0.60	0.29	
7/8	0.96	0.69	0.35	
17/18	0.73	0.93	0.63	

PPV: positive predictive value

AUC: area under the curve, CI: confidence interval

* Maximum score is 31 when proposed weighting scores is adopted

Table 7. Test-retest reliability for each cut-off value of the screening questionnaire

Cut-off value of the screening questionnaire	Kappa (\pm S.E.)
Adoption of reference weighting scores 41/42	0.50 \pm 0.08
Adoption of proposed weighting scores 5/ 6	0.41 \pm 0.09
7/ 8	0.55 \pm 0.08
17/18	0.56 \pm 0.08

inconsistency in the answers to question 2 between the two test administrations. In the retest control group, the kappa index for questions 2 and 7 were as low as 0.06 and 0.07, respectively, with other questions showing comparatively better agreement indices.

III. Evaluation of the Weighting Scheme

Weighting scores in our study design were calculated using the odds ratios of cases and control groups (Table 4). The distribution of weighting scores in our study ranged from 2 to 6.

IV. Validity of the Screening Questionnaire

When the weighting proposed by the Duarte study was applied to each question, the sensitivity of the questionnaire was 0.48, the specificity was 0.95, and the positive predictive value was 0.23 with a cut-off value of 41/42 (equal or less 41, equal or more 42) (Table 5). When the new weightings were used, the optimum cut-off value was 7/8. The sensitivity was then 0.93, with a specificity of 0.71 and a positive predictive value of 0.08. When the cut-off value was set to 5/6, the sensitivity was 0.98, with a specificity of 0.61. When the cut-off value of 17/18 was used, the sensitivity was 0.50, with a specificity of 0.95.

When the two weighting schemes were compared, the new scheme showed a higher area under the curve (0.902, 95% CI=0.868-0.935) compared to that of the original weighting scheme (0.877, 95% CI=0.835-0.920)(Figure 1).

For validation of the new weighting schemes were used, we applied new weightings to the retest data. Data of retest group were showed similar results as the validity of initial study (Table 6). But, control group in retest were randomly selected among the non-PD control group. This selection could not represent the whole distribution and prevalence in the cluster population structure. And, retest group had a limitation that base population was same as initial study. Because of these limitations, positive predictive values in validation of retest group were more increased than initial study.

V. Test-Retest Reliability after Classification According to Cut-Off Value

When we adopted the reference weighting scores, the kappa for test-retest reliability with the 41/42 cut-off value was 0.50 (95% CI=0.42-0.58) (Table 7). When we adopted our proposed weighting scores, the kappa statistic for test-retest reliability of the 5/6, 7/8, and 17/18 cut-off values were 0.41 (95% CI=0.32-0.50), 0.55 (95% CI=0.47-0.63), and 0.56 (95% CI=0.48-0.64), respectively.

DISCUSSION

For a community survey on neurodegenerative

disorders, validation of a screening tool's reliability and validity is an essential first step. The validity and reliability of a given questionnaire will be different in various cultures, regions, and populations. In this study, we assessed the validity and reliability of a screening questionnaire designed for both hospital-based and community-based subjects. To be used in a Korean community, we modified the weighting scores of the screening questionnaire based on the survey. When our new weighting scheme was applied, the validity was higher with a simultaneous improvement in reliability.

This study shows some differences in response in the community group when compared to previous studies of hospital groups. When using a score of 41/42 as the cut-off value, Duarte et al. reported that both sensitivity and specificity were 1.00. Because these results were based on literate hospital PD patients, they do not entirely reflect the circumstances in a community setting, especially considering the higher prevalence of illiteracy in the elderly population and the less standardized interview environment [12]. When we used the weighting scheme proposed by Duarte et al., the questionnaire was not adequate as a screening tool because of a very low sensitivity. Another study using Duarte's weighting scheme in the same questionnaire also reported low sensitivity and specificity [16]. After adopting new weighting scores and using a score of 5/6 for the cut-off value, the sensitivity was improved to 0.98 and the specificity was acceptable at 0.61 for surveying prevalence in a community. This suggests that the characteristics of PD patients are different in various settings. In PD patients in the Korean community, the proportion of positive answers regarding symptoms was smaller than in the hospital groups of a previous study [12]. Also, the illiteracy rate in the elderly population in this study was about 15% and was even higher in the rural communities.

The kappa statistic is a quantitative method for assessing the agreement between repeated surveys. The kappa range for the screening questionnaire in our study, with the exception of items 2 and 7, was 0.20-0.60, representing fair and moderate repeatability [17,18]. The method of assessing agreement in a test-retest study can be complicated by recall bias and confounded by combined cognitive impairment, which tends to be more common in the elderly [19]. The kappa range for items 2 and 7 of screening questionnaire in retest control group

was 0.06-0.07. But range of agreement percent was 72.7-85.0, representing good agreements. These results were made by "kappa paradox." The reason for the discrepancy between agreement percent and kappa was low frequency of positive answers in retest control group. When positive answers were low frequency in each item of questionnaire, very low values of kappa could not reflect low percent of agreement.

We found several problems with question 1 related to "rising from a chair," and also with question 2, related to "writing a letter." First, many elderly people living in rural areas do not use chairs in their homes [20]. We could consider the replacement question "do you have difficulty turning or rising in bed or bedclothes?" instead of "do you have trouble arising from a chair?" in question 1. Second, some participants hesitated to answer the question related to letter-writing because they were illiterate and were thus incapable of writing letters. Levels of literacy in elderly people is an important factor for answering the screening questionnaire [20]. In the future, researchers will need to modify these questions for a more community-based use.

Our study aimed to distinguish patients with PD from normal subjects through the administration of a community questionnaire. The use of screening tools in a population survey is inevitable because door-to-door surveying requires cost and time [21]. The questionnaire usually needs to have high sensitivity and specificity. Low sensitivity would produce false negatives whereas low specificity would lead to false positive subjects [12]. Bias due to low sensitivity would under-estimate the prevalence of disease [22]. Although an ideal screening tool would have 100% sensitivity and 100% specificity, screening tools with high sensitivity are likely to be less specific, and vice versa [23]. However, since the objective of a screening questionnaire is to reduce the total number of subjects that need to be examined by an expert, low specificity could be accepted in a community survey [24].

This study had several limitations. Repeated secondary interview for control group was conducted by same interviewers as first phase, but, case group was conducted by different interviewers. These changed interviewers could make a difference in judgment about answers and methods of interview. Proportion of agreement in answers could be affected by these differences in test-retest study. The interval between test

and retest was different between the PD patient group (seven days later) and the control group (90 days later). We presented the results of testing and retesting separately, because these differences in duration could cause recall bias. Another problem with PD screening by questionnaire is the occurrence of false negatives and false positives. We made efforts to minimize false negative cases by using an alternative method to detect the cases, including past history, and by training the interviewers to observe posture and movement closely, methods which could be effective in detection of the neglected community PD cases. Secondly, we adopted the weighting scores to exclude the other forms of parkinsonism or deficits from other causes. Validity of the questionnaire in this study was increased and also similar results were reported in retest group, but these could be yielded because new weighting schemes got from the existing states in our subjects.

The sampling method used in this study was well designed to represent the demographics of the whole community in a mixed urban and rural area. In each step of the sampling, we randomly selected the subjects after considering the distribution and characteristics of the basic administrative districts. We conducted this study with three phases in order to minimize missing patients. Comprehensive detection of the patients included examination of all the possible suspected cases through three phases of examination, with complete examination of all subjects with suspected disease by a highly trained neurologist. Our results are the first report validating this screening tool in Korea. This questionnaire could help later epidemiologic studies of PD in the Korean community.

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Appendix. Screening questionnaire for Parkinson's disease (Korean version)

질 문	예	아니오	모르겠음
1. 의자에서 일어나는데 힘이 드십니까?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. 글씨의 크기가 예전보다 작아졌습니까?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. 남들이 목소리가 예전보다 작아졌다고 하십니까?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. 걸을 때 몸의 균형을 잡기가 힘드십니까?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. 문 밖으로 나가는데 갑자기 걸음이 떨어지지 않은 적이 있으십니까?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. 과거보다 얼굴 표정이 없어졌습니까?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. 팔이나 다리를 떠십니까?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. 옷을 입을 때 단추를 끼기가 힘이 드십니까?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. 걸을 때 다리를 끌고, 걸음이 점점 작아지십니까?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>