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Citation	Acta medica Nagasakiensia. 1997, 42(3-4), p.34-38
Issue Date	1997-12-20
URL	http://hdl.handle.net/10069/16089
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Acta Med. Nagasaki 42 : 34−38

The Development of a Self-rating Questionnaire for Screening Dementia

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Few self-rating questionnaires have been developed for use in screening for dementia due to technical difficulties. We were required to develop a self-rating questionnaire for dementia for the first-stage screening of a 1995 dementia prevalence study in the Nagasaki Prefecture. In our pilot study, we drafted a questionnaire of 43 items and applied it to 399 subjects in attendance at educational programs for senior citizens, and residing in institutions for senior citizens and in nursing homes for the aged. 185 subjects (71 males, 114 females ; average age, 77.3 years) successfully completed the questionnaire, including 39 subjects with medically diagnosed dementia. We conducted a discriminant analysis on these subjects' responses to the original 43 items, and extracted 13 items which most contributed to discrimination of dementia. The sensitivity of discrimination by the final questionnaire was 0.82, and the specificity was 0.89.

In the prevalence study of dementia in Nagasaki Prefecture, we could re-examine the validity of the questionnaire. The high sensitivity and moderate level of specificity of the questionnaire was considered reasonable for use in screening dementia.

Key words : prevalence, self-rating questionnaire, dementia, sensitivity, specificity

Introduction

A number of intellectual function tests have been developed for evaluating dementia. Among the best known are the Mini-Mental Status Examination[1] and the Clinical Dementia Rating Scale[2]. In Japan, the Karasawa's Clinical Criteria for Grading of Dementia (CCGD)[3] and the revised version of Hasegawa's Dementia Scale (HDS-R)[4] has also been widely used. The validity of these scales has been established, and they have been used both for screening dementia and in epidemiological studies on dementia. Due to technical difficulties, however, for fewer self-rating questionnaires have been developed for dementia. It remains the case that patients with dementia have few insights into their subjective experiences, and little capacity for describing them. For example, objective symptoms such as behavioral changes and a lowering of activity in daily living (ADL) are important for dementia diagnosis, though patients often fail to recognize them. Such limitations make the development of self-rating dementia questionnaires problematic, and indeed, few useful questionnaires exist.

The authors have organized a 'Study Group of Problems of People with Dementia' (chair by Y.O.) at the request of the Nagasaki Prefecture in 1995, and used it to investigate the prevalence of dementia in the Nagasaki Prefecture. Due to financial limitations, we used a self-rating questionnaire to screen subjects in the first stage of our study. Our goal was to develop a highly sensitive self-rating questionnaire capable of detecting even mild or potential cases of dementia.

Most conventional prevalence studies have been conducted on elderly patients of 65 years of age or older[5]. In actual clinical settings, howevers, there are frequently dementia cases of onset age earlier than 65. In most early onset cases, a majority of family members do not recognize the early symptoms of the disease and thus fail to provide appropriate care. At the same time, they tend to enduce a greater burden than those families in which the onset occurs later in life[6]. In this study, we therefore included people 60 years old and over as subjects .

In order to meet the requirements indicated by the Nagasaki Prefecture, we tried to develop a questionnaire which was easy to answer and which could detect mild dementia cases without significant behavioral problems and unrecognized as dementia by family members. It was thus necessary to establish a self-rating dementia questionnaire of high sensitivity rather than high specificity.

Subjects

The 399 subjects of the pilot study included 48 people over 60 years old who were attending senior educational programs, 55 people over 60 years old who were attending lectures for senior citizens, 176 people residing in institutions for senior citizens, and 120 people residing in nursing homes for the aged (129 males and 261 females, 9 sex unidentified cases) (Table 1). An subjects gave informed consent prior to participation in the study. The average ages were 77.3 ± 1.2 years for males, 81.0 ± 3.2 years for females, and 79.8 ± 1.3 years in total. Family members of subjects residing at home and staff members of subjects residing in institutions were also asked to participate in

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the study.

Methods

We prepared a draft of a dementia questionnaire consisting of 43 items on clinical history, present illness (cerebral infarction, diabetes mellitus, hypertension, and heart diseases), activity of daily living (taking food, dressing, walking, bathing, and control bladder and bowel), and condition of daily life (occupation, degree of attendance at social events, and range of activity). Intellectual function tests for detecting such conditions as disorientation, disturbance of memorization, and abstract thinking. We originally established the test items concerning intellectual function referring to conventional intelligence tests[7], and dementia rating scales[8].

We also prepared a questionnaire consisting of 29 items for family members of subjects residing at home and staff members of subjects residing in institutions. The questionnaire included items concerning subjects' clinical history, present illness, nuclear dementia symptoms such as disturbance of memorization and disorientation, and accessory dementia symptoms and signs such as abnormal behavior, delirium, emotional incontinence, delusion, and hallucination. The responses of family and staff members were used to select subjects for the second stage survey.

We applied the questionnaires to the 399 subjects and the members of their families or staffs, and requested that they answered without discussion among them. People attending the weekly senior educational programs answered the questionnaire at the program sites. For their family members the questionnaire was distributed via the attendants and collected at the next meeting. For the residents of senior-citizen institutions and their respective staffs, the questionnaire were hand-delivered and collected one week later.

Diagnosis of dementia of institution resident was made according to the diagnoses of the subjects' doctors and the evaluations of staff members. Diagnosis of attendants of senior educational programs was made based on interviews conducted by psychiatrists at the program sites, and by referring to family members' evaluations. The focus of evaluation by family or staff members was on the question "Do you sometimes suspect that he/she might have dementia?".

The appropriate numbers of questionnaire items for subjects was estimated to be around ten and was a trade-off between response rate and sufficient information for screening dementia. Subjects answering more than 22 of the 43 items were chosen for analysis. The final item on the questionnaire consisted of a chice between "I read and answered this myself" I had someone read this and answered it myself", and "I had someone else answer this for me". The former two responses were taken as valid for subject inclusion. Among all 43 items, 13 were found to contribute to the discrimination between those with and without dementia by stepwise discriminant analysis using the statistical program package BMDP. We also obtained the coefficient for each item and a constant by a linear discriminant function (Figure 1) that minimized the overlapping of distributions between the two groups.

Figure 1. linear discriminant function

$$y = \sum_{i=1}^{13} a_i x_i + b$$

a 1	: −1. 0 8 4 0 5
a 2	: 0. 6 9 0 5 2
a 3	: −0. 7 8 3 4 8
a 4	: −0. 8 2 4 1 6
a 5	: −0. 8 1 1 9 0
a 6	: −0. 6 2 1 4 5
a 7	: −0. 8 8 3 2 9
a 8	: −1. 1 3 8 1 3
a 9	: −0. 9 4 6 6 0
a 1 0	: 1. 4 3 2 0 2
a 1 1	: 0. 7 0 1 8 8
a 1 2	: −1. 7 5 6 6 5
a 1 3	: −0. 0 2 9 4 3
b	: 3. 1 5 0 4 5

Results

Among the 399 subjects, 185 gave valid answers and were useful for the data analysis. These included 71 males and 114 females (39 people with dementia and 146 people without). The average age was 74.9±7.1 for males, 78.8 ±7.4 for females, and 77.3±7.5 in total.

The 13 items selected as those most contributing to dementia screening were as follows :

1. When making calculations involving money, do you often make mistakes that people mention to you?
2. Do you sometimes forget how to use common appliances, such as the television, telephone or gas stove, or make mistakes when using them?
3. What is the date of Adult Day? (Adult Day is a national holiday in Japan.)
4. What year is it now?
5. Which is further, Osaka or Nagoya, from where you live?
6. Please complete this sentence by placing an appropriate word in each set of brackets.

   Let's go ( ) train ( ) there is heavy traffic.
7. Copy the geometrical figure shown. (Two stacked pentagons are depicted).

8.9.10. How many blocks are piled in the figure?

11. Do you often have trouble sleeping?
12. How old are you? (Check whether age is written in.)
13. Item 13 consists of the actual age of the subject.

The answers were transformed into dichotomous data. That is, for items 1, 2, and 11, a response of *no* was scored

Figure 2. The distribution of non-demented group and demented group

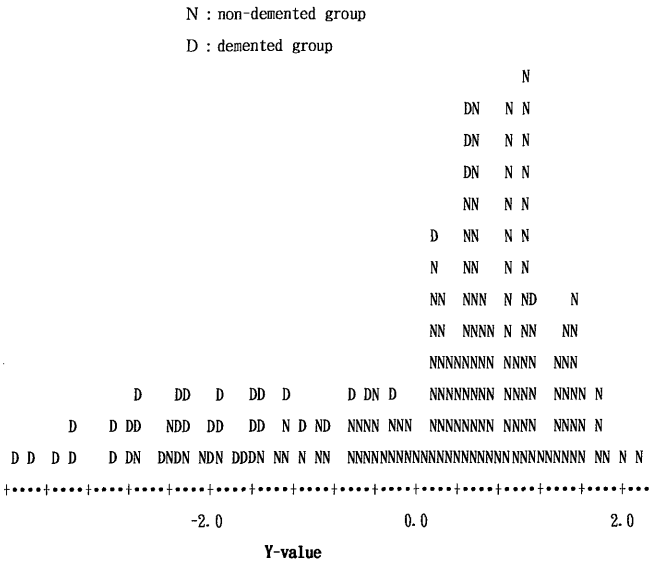

Table 1. Subjects

	numbers	average age
senior educational programs	48	69.8
lectures for senior citizens	55	74.2
institutions for senior citizens	176	83.4
nursing homes for the aged	120	81.1
Total	399	79.8

Table 2. The comparison between the results of the questionnair and clinical diagnosis (N=185)

	clinical diagnosis		Total
questionnaire	demented	non-demented	
demented	32	16	48
non-demented	7	130	137
Total	39	146	185

Table 3. The comparison between the results of the questionnair and clinical diagnosis (N=335)

	clinical diagnosis		Total
questionnaire	demented	non-demented	
demented	130	83	213
non-demented	12	110	122
Total	142	193	335

Table 4. The comparison between the results of the questionnair and clinical diagnosis (in the prevalence study)

	clinical diagnosis		Total
questionnaire	demented	non-demented	
demented	141	55	196
non-demented	8	100	108
Total	149	155	304

0 and a response of *yes* was scored 1 ; for items 3-10, a correct response was scored 0 and an incorrect response 1 ; and for item 12, if any response was given the item was scored 0, while the absence of a response was scored 1. The subject's actual age was taken as the score for item 13.

In X1 to X13 of the linear discriminant function (Figure 1), the score of each question was inserted, and cases with positive or negative Y values were judged as "non-dementia" or "dementia" cases, respectively. Figure 2 shows the total scores of 185 subjects and the distribution of the normal and dementia groups. The axis of the abscissa represents the total scores (Y), with negative values being to the left and positive to the right. As can be seen, many normal cases are distributed on the positive side and many dementia cases on the negative side.

Table 2 compares the diagnoses indicated by the questionnaire with those determined clinically. The comparison between these two methodologies showed that the questionnaire had a sensitivity of 0.82 and a specificity of 0.89, which results validated the inclusion of the above 13 items in our final questionnaire for screening dementia.

We next applied this calculation to the 335 people who answered the 13 questions, including cases excluded from the previous analysis, and judged the existence of dementia by the linear discriminant function. By comparison of the results of the 335 people and their clinical diagnoses (Table 3), we obtained a sensitivity and specificity of 0.91 and 0.56, respectively. The specificity was low because the discriminant function made a false positive judgment for 83 people, which suggests that this questionnaire tended to include dementia cases too sensitively. However, considering the purpose of this investigation, which was to screen mild dementia, the questionnaire satisfied its purpose.

Next, we examined the validity of the questionnaire in regard to the prevalence of dementia in the Nagasaki Prefecture. This investigation consisted of a first-stage and second-stage investigation ; in the first stage, dementia was screened using the questionnaire (for subjects and for their family members or caregivers), and in the second stage, interviews by psychiatrists and community nurses were used. The first-stage subject group comprised 4368 people, of whom 3965 (90.8%) completed the first stage, while the second-stage subject group comprised 530 candidates consisting of those suspected of having dementia and 68 people who were 2%, required by epidemiological theory, among people that were not suspected of dementia. In judging those subjects suspected of having dementia for the second-stage survey, poor answers and key information from family and institution staff members, as well as negative results of the discriminant function of questionnaire, were considered. 422 out of 530 people completed the second-stage survey. The CCGD and HDS-R ratings and interviews of a public health nurse and psychiatrist were conducted in the second-stage survey, and psychiatrists referred to these results and interviews when making their

diagnoses.

Table 4 shows the comparison between the results of 'dementia' judgment by linear discriminant function and the diagnosis by psychiatrists for 304 people who gave valid answers to the screening questionnaire in the first stage among the 422 people who completed the second stage. The results (sensitivity, 0.96 ; specificity, 0.64) were similar to those obtained in the pilot study. That is, the sensitivity was very high and the specificity was moderate.

Discussion

The authors tried to overcome the demerits of a self-rating questionnaire as much as possible and to establish a questionnaire of quantifiable validity. The following three aspects of a valid questionnaire, defined by Benett et al[9], were used as a reference.

1. Relevance : Does the questionnaire obtain the information it was designed to seek?
2. Completeness : Was all desired relevant information obtained?
3. Accuracy : Can reliance be placed upon the responses to the questions?

In order to confirm validity of our questionnaire, we calculated both sensitivity and specificity. As shown in Table 4, the sensitivity was high, exceeding 0.9. That is, when the questionnaire was used for people who were clinically diagnosed as having dementia, it was confirmed to have a high rate of success in estimating 'dementia'. However, the specificity was moderate, approximately 0.6, which indicates that the questionnaire could include false positive. That is, the questionnaire could include people who are not suffering dementia, such that if there were a very large number of subjects and limited manpower, it would be better to use other information devices and to narrow the number of subjects. However, high sensitivity could make up for low specificity to some extent, in which case this questionnaire would meet the requirements of a screening. In this sense, the questionnaire can be considered useful, reasonable, and equal to the requirement of "a questionnaire of high sensitivity for detecting mild and potential dementia even of low specificity" as dictated by the Nagasaki Prefecture.

Advantages and disadvantages should be understood and traded off when using a self-rating questionnaire. Compared to the amount of information one can obtain by an interview conducted by a specialist, the information obtainable via questionnaire is limited. For example, objective information on such factors as facial expression, manner of response, and tone of voice cannot be obtained through a questionnaire. Schlesselman[10] has described the following five advantages of a self-rating questionnaire.

1. General standardization in the presentation of material
2. Elimination of interviewer bias
3. Reduced cost through savings in time and effort in administering
4. Easier questioning of large numbers of persons
5. More leisurely, and possibly more careful, responding allowed.

In our study, advantages number 3 and 4 were particularly applicable. Schlesselman also listed six disadvantages and stated that there were more disadvantages than advantages in the use of a self-rating questionnaire.

1. General limitation to only simple, closed, and restricted choice questions
2. Requirement of a high rate of literacy and reading ability
3. Inability to probe for subtleties or qualification of response
4. Lack of assurance that the questionnaire is answered by the intended respondent, and alone
5. Lack of opportunity to observe emotional responses
6. Inability to clarify questions or responses.

In our study, we compensated for disadvantages 1, 3, 5, and 6 by use of information from family members and staff members, and by use of the second-stage interview. Regarding disadvantage 4, we added an item to confirm the identity of the respondent, and excluded cases accordingly.

In regard to disadvantage number 2, literacy deficiencies were compensated for by conducting interview.

Looking at answering rates, the number of question items in the draft questionnaire was 43, and because of that, the answering rate of the pilot study was only 46.4% (185 of the 399 subjects answered all the questions). In the investigation using the 13 item questionnaire, the answering rate rose to 72.4% (304/422). The number of question items, 13, was considered appropriate.

Another problem was the interpretation of unwritten replies, i.e., determining whether these were due to a subject refusing to answer the questionnaire or to a failure to understand the questions. When no answers were written for the 13 questions, unless the reason for not writing answers was specifically written, such as, "I cannot answer because I cannot understand the questions" or "He/She cannot make communication" or due to a lowering of ability, then we decided that the person refused to answer. However, we still need do consider further how we judge cases with unwritten answers.

Kitamura[11,12], indicated "social desirability" as another limitation of self-rating questionnaires. That is, people tend to give a socially favorable answer when the content of a question concerns private or delicate subjects. In establishing our questionnaire, we tried to lessen the effects of social desirability. In our investigations, some people tried to answer favorably, worrying they might be diagnosed as having dementia. For example, even when they often forgot things, they answered "no", or "not

having insomnia", even when this was not the case, or they asked other family members to write their answers. We corrected such biased answers most probably occurring due to the need for social desirability by confirming answering situations from subjects and information from family members. There were many false positive cases when the self-rating questionnaire alone was used, so in the investigation we also conducted dementia screening using information from the questionnaire for family members.

Thus, the present self-rating questionnaire developed for determing dementia prevalence is here proven valid and useful for sensitive screening of potential dementia, though it shows only a moderate level of specificity.

Summary

In prior to the dementia prevalence study of Nagasaki Prefecture, we established a self-rating questionnaire for screening dementia and examined its validity.

1. We asked 399 subjects and their family members or staff members to answer a 43-item draft questionnaire, and we conducted a stepwise discriminant analysis on 185 people who gave valid responses, then selected the 13 question items that most contributed to the discrimination of dementia for use in our final questionnaire.
2. Application of the final questionnaire to 185 cases gave a dementia discrimination of 0.82 sensitivity and 0.89 specificity.
3. In our study of dementia prevalence in the Nagasaki Prefecture, we conducted the second-stage interview using conventional assessment scales for dementia with 422 subjects, and we examined the validity again with 304 people who gave valid responses. Sensitivity was 0.96 and specificity was 0.64. This suggested that our self-rating screening questionnaire satisfied the purpose of the study.

Acknowledgements

We want to express our gratitude especially to the participants and their family, and the staff of institutions.This study was supported by Longevity measures division of Nagasaki Prefecture.

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