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Development of an activity of daily living scale for patients with chronic obstructive

pulmonary disease: the Activity of Daily Living Dyspnea scale (ADL-D scale)

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Summary at a Glance

The study describes the development and evaluation of the Activity of Daily Living Dyspnea scale (ADL-D scale), a novel activity of daily living (ADL) scale for patients with chronic obstructive pulmonary disease (COPD).

The results of this study indicate that scores obtained with the ADL-D scale correlate with measures of exercise tolerance (distance walked on the Incremental Shuttle Walking Test), health-related quality of life (responses to the St George's Respiratory Questionnaire) and severity of functional limitation due to dyspnea (Medical Research Council dyspnea grade) and provide consistent results when completed by patients with COPD.

The use of our ADL-D scale can form the basis of ADL evaluation, and may assist in developing an individualized respiratory rehabilitation program.

ABSTRACT

Background and objective: Patients with chronic obstructive pulmonary disease (COPD) often experience restriction in their activity of daily living (ADL) due to dyspnea. This type of restriction is unique to patients with COPD and cannot be adequately evaluated by the generic ADL scales. The objectives of this study were to develop an activity of daily living scale (the Activity of Daily Living Dyspnea scale [ADL-D scale]) for patients with COPD that is easy-to-use, consists of activities common to the majority of patients, and reflects impairment in ADL; and to investigate its validity and internal consistency.

Methodology: 83 male patients with COPD completed a pilot 26-item questionnaire. Subjects also performed the Incremental Shuttle Walk Test (ISWT), and completed the St George's Respiratory Questionnaire (SGRQ), and Medical Research Council (MRC) dyspnea grade.

Results: 8 items that were not undertaken by the majority of subjects, and 3 items judged to be of low clinical importance by physical therapists were removed from the pilot questionnaire. Consequently, the final ADL-D scale contained 15 items. Scores obtained with the ADL-D scale were significantly correlated with the MRC dyspnea grades, distance walked on the ISWT and SGRQ scores. The ADL-D scores were significantly different across the five grades of the MRC dyspnea grade. The ADL-D scale showed high consistency (Chronbach's α coefficient of 0.96).

Conclusions: The ADL-D scale is a useful scale for assessing impairments in ADL in Japanese male patients with COPD.

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Key Words: activities of daily living, chronic obstructive pulmonary disease, dyspnea, Questionnaire, scale.

Short Title: Development of the ADL-D scale

INTRODUCTION

As chronic obstructive pulmonary disease (COPD) progresses, patients often experience dyspnea during activity of daily living (ADL) and as a consequence may develop fear and anxiety prior to performing these activities. This leads to avoidance of the ADL that elicit dyspnea and a gradual decline in the patient's ability to perform ADL. ¹⁻⁵

In clinical practice, impairment in ADL is usually evaluated using generic ADL scales such as the Barthel index. However, the disability associated with ADL in COPD differs from that in other conditions because patients with COPD often discontinue an activity due to dyspnea although they retain the physical capacity to undertake the activity. Thus a valid evaluation of impairment of ADL in patients with COPD using a generic ADL scale is limited and there is a need to develop ADL scales that are specific to the causes of ADL impairment in such patients. Several ADL scales for patients with COPD have been developed. These include the University of California, San Diego Shortness of Breath Questionnaire (SOBQ), the modified version of the Pulmonary Functional Status and Dyspnea Questionnaire (PFSDQ-M), the Functional Performance Inventory (FPI), 10 the London Chest ADL Scale (LCADL), 11 the Nagasaki University Respiratory ADL questionnaire (NRADL), 12 the chronic obstructive pulmonary disease activity rating scale (CARS), ¹³ and the Activities of Daily Living Using Upper Limb Score (ADL-U Score). 14 Of these scales, the SOBQ, PFSDQ-M, FPI, and LCADL are not appropriate for use in Japan because the activities assessed in these questionnaires do not correspond to the lifestyle of Japanese patients. Conversely, the NRADL, CARS and ADL-U Score were developed in Japan. However, the NRADL

was designed only for use in hospitalized patients, and has not been validated for use in outpatients. Further, the NRADL focuses mainly on ambulatory activities and is not adequate for evaluating activities that involve the upper limbs. Another limitation is that the NRADL is completed via an interview and is time consuming. The CARS assesses the amount of assistance required to perform ADL and not the severity of dyspnea during ADL. The ADL-U Score is a self-administered questionnaire that we developed and contains 11 items that focus on the self-care ability using the upper limbs. The ADL-U Score significantly correlated with the NRADL and six-minute walk distance, showed significant differences among dyspnea classifications, and had a Chronbach's α coefficient of 0.98. This evaluation suggests the ADL-U Score is valid and has high internal consistency.¹⁴ However, the ADL-U Score is limited in its use because it does not evaluate ADL that involve ambulation.

An assessment tool is required that is an easy-to-use, consists of activities common to the majority of patients, and which reflects ADL impairment in patients with COPD. To achieve this objective we developed the Activity of Daily Living Dyspnea scale (ADL-D scale) and investigated the validity and internal consistency of this new scale.

METHODS

Subjects

The subjects for this study were recruited from patients participating in pulmonary rehabilitation programs at 7 hospitals and 3 clinics in Japan who had stable COPD. Subjects who experienced difficulty in understanding or completing the questionnaire; those with cardiovascular disease (e.g. cardiomyopathy, vascular disorder, poorly-controlled severe heart failure, acute myocardial infarction and severe arrhythmias); disabling orthopaedic conditions; cerebrovascular disease; and those with a history of an acute exacerbation of COPD within 3 months prior to the study were excluded. The sample comprised 83 males of whom 20 participated in the pilot study.

The study was approved by the Human Research Ethics Committees in each clinical facility, and written informed consent was obtained from all subjects prior to data collection.

Measurements

Subjects completed the following assessments.

The Medical Research Council (MRC) dyspnea grade

The severity of functional limitation due to dyspnea was evaluated using the MRC dyspnea grade. 15

The Incremental Shuttle Walking Test (ISWT)

Functional exercise capacity was evaluated using the ISWT, ¹⁶ in the 56 subjects who were not receiving supplementary oxygen. Subjects performed the ISWT twice separated by a rest period of at least 30 min to allow recovery of dyspnea to their pre-test level. Criteria for terminating the ISWT were intolerable dyspnea, failure to maintain the required walking speed or percutaneous oxygen saturation of less than

85%.

The St. George's Respiratory Questionnaire (SGRQ)

Health-related quality of life (HRQOL) was assessed using the SGRQ,¹⁷ a self-administered scale that consists of 53 items measuring "activity", "impact" and "symptoms". A total score is also reported.

Development of the ADL-D scale

Figure 1 summarizes the stages involved in the development of the ADL-D scale.

Preparation of a pilot 26-item questionnaire

Open-ended interviews were carried out with 20 males with COPD to determine ADL that were likely to cause dyspnea. A pilot 26-item questionnaire was generated using data obtained from these interviews and from a review of previous tools developed to assess health and functional status. A 5-point (0-4) response choice for each item was provided for subjects to rate the severity of dyspnea when performing each activity; "4: Not at all", "3: Slight", "2: Severe", "1: Very severe", and "0: Maximally severe". In addition to these choice options, a response "X: Not necessary to do (It is not necessary to do this activity for me)" was provided. When subjects answered "X: Not necessary to do", the item was regarded as having a missing value, and to enable standardization of the total score where this occurred subjects were requested to estimate the level of dyspnea using a 5-point ("4: Not at all", "3: Slight", "2: Severe", "1: Very severe", and "0: Maximally severe") scale if they were to undertake the activity.

Once the purpose of the questionnaire was explained, the subjects were asked to complete the pilot 26-item questionnaire. Subjects completed the pilot questionnaire and the other measurements previously described in random order within a two week period. The 20 patients included in the pilot study also participated in the subsequent validation

study.

Item selection

We selected items based on three criteria. First, if the items were regarded as "Not necessary to do" by 20% or more of subjects, we judged them to have no practical use (*Not appropriate*) and eliminated these items. Second, if the items had no significant (P>0.05) correlation (assessed using Spearman rank correlation coefficient) with the MRC dyspnea grade, we judged them to have no relation to severity of dyspnea and eliminated the items (*Unrelated to global health*). Third, we explained the purpose of the study to 13 physical therapists (who had between 3 and 20 years of clinical experience in respiratory rehabilitation), and asked them to assess the clinical importance of each activity item using one of the following responses: "It should be contained in the questionnaire", "I am not sure whether it is important" and "It can be eliminated". If the items were regarded as "It can be eliminated" or "I am not sure whether it is important" by 50% or more of the therapists, we eliminated the items. The remaining items were used as the core activities of daily living items of the ADL-D scale.

Examination of the validity and internal consistency of the ADL-D scale

Concurrent validity of the ADL-D scale was examined by comparing relationships between the total score on the ADL-D scale and MRC dyspnea grades, distance walked on the ISWT and SGRQ scores (for each subscale and total score). Discriminative validity of the ADL-D scale was assessed by comparing the ADL-D scores with the MRC dyspnea grades. In addition, the extent to which the ADL-D scale provided a comprehensive evaluation of ADL was examined by correlating the ADL-D scores and scores obtained from the pilot questionnaire that included 26 items relating to ADL.

Internal consistency was determined based on the extent to which the different items on the questionnaire measure the same construct and this was expressed for the ADL-D scale.

Statistical Analyses

Spearman rank correlation coefficients were used to measure the magnitude of association between variables. Mann-Whitney's U test was performed to examine the ADL-D scores among subjects grouped according to their MRC dyspnea grade. Chronbach's α was used to test internal consistency of the ADL-D scale.

Data were analyzed using SPSS (version 11.5), and a probability (P) of < 0.05 was regarded as statistically significant.

RESULTS

Table 1 shows the characteristics of the 83 males subjects that participated in the study. The ages of the subjects ranged from 55 to 86 years and subjects had a range of severity of COPD. The MRC dyspnea grades of the subjects were: grade 1(n = 9), grade 2(n = 34), grade 3(n = 19), grade 4(n = 12), grade 5(n = 9). There were no significant differences in any of the measured variables between the subset of 20 males who participated in the development of the pilot questionnaire and the total subject cohort that participated in the validation study.

Item reduction

We eliminated 8 items from the pilot questionnaire because they were reported as "Not necessary to do" by 20% or more of subjects. These 8 items were: "Hanging the laundry up to dry (45.2%)", "Vacuuming the floor (41.7%)", "Sweeping the floor with a broom (41.7%)", "Wiping a table (32.1%)", "Wiping the floor (54.8%)", "Lifting a heavy object from the floor to a table (20.2%)", "Hanging the futons up to dry (29.8%)", and "Carrying a heavy object (21.4%)". All of the items included in the pilot questionnaire showed significant correlations with the MRC dyspnea grades (r = -0.53) to -0.76, P < 0.001. An additional 3 items were eliminated on the basis of lack of "clinical significance"; these items were: "Standing up from sitting position on the floor (54%)", "Washing a towel or kitchen cloth by hand (100%)", and "Taking an object from a high place (62%)". Consequently, the final ADL-D scale contained 15 items and is scored from 0-60, with a score of 60 signifying no dyspnea.

Validity and internal consistency

The average score obtained by on the ADL-D scale was 46.7 (SD: 11.5, range: 14-60). Table 2 shows the correlations between the ADL-D scores and the MRC

dyspnea grades, distance walked on the ISWT and SGRQ scores. Significant correlations were found between all of the measures. The ADL-D scores were most strongly correlated with the activity domain on the SGRQ and in contrast the association with SGRQ (symptoms), although significant, was weaker than all other correlations. The correlations between the ADL-D and MRC dyspnea grades and the distance walked on the ISWT were stronger than the correlations between SGRQ (activity) scores and these same variables.

The ADL-D scores were significantly different across the five MRC dyspnea grades (Figure 2). This observation was most evident among subjects with MRC grades 3-5.

A strong linear correlation was found between the ADL-D scores and responses to the pilot questionnaire that included all 26 items (Figure 3).

The ADL-D scale showed a high degree of internal consistency with Chronbach's α coefficient of 0.96.

DISCUSSION

In this study we recruited male, Japanese patients with COPD to develop the ADL-D scale, a novel ADL scale. We consider this scale to be superior to previous scales because it is concise and can be completed in only a few minutes by patients alone. Furthermore, it is designed to reflect specifically the ADL restriction experienced by Japanese males with COPD. The findings of this study indicate that scores obtained with the ADL-D scale correlate with the distance walked on the ISWT, SGRQ scores and MRC dyspnea grades and provide consistent results when completed by Japanese male subjects with COPD.

During the process of developing this new scale, we eliminated activity items that were not often performed by our subjects, and focused on items that are the most common in daily life and undertaken by the majority of subjects. We believe that this process resulted in an ADL scale that is more applicable to a wide range of Japanese males with COPD. A similar process was used by Lareau et al who removed items from the PFSDQ that were not performed by 20% or more of subjects to develop the PFSDQ-M. In this study, we eliminated 8 items that were not performed by 20% or more of subjects such that the ADL questionnaire consisted of the items that were applicable to the majority of Japanese males. For clinical applicability, ADL questionnaires should contain the minimum number of important items and be quick and easy to complete. In previous studies, 11,14 the selection of items included in ADL questionnaires was determined by statistical factor analysis, and was not based on the opinions of patients and experienced physical therapists. In this study, we considered the views of experienced physical therapists as well as the results of statistical analyses when developing a scale that included only the most relevant items. Therefore, the 3

items judged to be of low clinical importance by the majority of physical therapists were eliminated from the final questionnaire. As a result, the ADL-D scale consists only of a small number of items (15 items), thereby decreasing the time needed for its completion, and the burden on the patient as well as the health professional in scoring the questionnaire.

In previous studies, it was reported that performance of ADL correlates with formal assessment of exercise tolerance and HRQOL in subjects with COPD. 19-24 Therefore, to assess the validity of the ADL-D scale, we hypothesized that scores obtained on the ADL-D scale would show a significant relationship with exercise tolerance, HRQOL and dyspnea severity. We found that the ADL-D scores were significantly correlated with the distance walked on the ISWT and scores obtained on the SGRQ. The ADL-D scores demonstrated a strong correlation with the SGRQ (activity) and a moderate correlation with SGRQ (symptoms). This is to be expected since the SGRQ (symptoms) evaluates symptoms such as cough, sputum production and wheezing, whereas the SGRQ (activity) is predominantly concerned with dyspnea. These results demonstrate that the ADL-D scale is a valid measure because patients with lower ADL-D scores had a greater impairment in functional exercise capacity and HRQOL. Moreover, the ADL-D scores showed a negative correlation with the MRC dyspnea grades. This suggests that the ADL-D scale can effectively discriminate between patients with different severities of dyspnea. A questionnaire with only a limited number of items is favored because it requires little time to complete though potentially may not collect sufficient information. However, we considered that by providing 5 response options the questionnaire would be sensitive while retaining the simplicity of the scale. The ADL-D scale and SGRQ (activity) measure the same concept (i.e. dyspnea during activities), the concurrent validity of the ADL-D scale was higher than the SGRQ (activity). We consider that the ADL-D scale will collect more detailed information on the severity of dyspnea during activities because the items have a 5-point response choice in contrast to the SGRQ that allows only a 2 point response choice ("Yes", "No"). In addition, although 11 items were eliminated from the pilot questionnaire, scores on the final ADL-D scale demonstrated a strong association with responses to the pilot questionnaire. Therefore, we consider that dyspnea during ADL will be comprehensively evaluated by using only the items retained in the final ADL-D scale.

The generally agreed upon critical value for the Cronbach's alpha is 0.70 or higher. ²⁵ Internal consistency was very high; which indicated that this questionnaire is an effective tool to measure dyspnea occurring during ADL.

Items in the ADL-D scale (see Appendix) are limited to the activities that patients with COPD commonly undertake, and includes activities involving ambulation and involving the upper limbs which in previous studies ^{3,5,14,26-28} have been associated with dyspnea. The use of our questionnaire could form the basis of ADL evaluation, and assist in developing an individualized respiratory rehabilitation program (i.e., the movement patterns associated with activities that elicit more severe dyspnea could be included in the exercise program).

The present study has some limitations. The study included only Japanese subjects with COPD and not other lung diseases, and as COPD is more common in males than females, all subjects were male. We recommend that evaluation of the ADL-D scale is undertaken in females with COPD and in subjects with other lung diseases. This evaluation should include subjects from other countries within Asia and elsewhere. In

addition, studies investigating the reproducibility of the ADL-D scale and its responsiveness to interventions such as pulmonary rehabilitation are required.

ACKNOWLEDGMENTS

We are grateful to Sue Jenkins, PhD, Associate Professor at the School of Physiotherapy, Curtin University of Technology for help in reviewing this manuscript. In addition, we are especially thankful to the staff of the following for their assistance in data collection: rehabilitation staff of Hozenkai Tagami Hospital, Isahaya memorial Hospital, Kounan Hospital, Nagasaki Pulmonary Rehabilitation Clinic, Nakamura Clinic, Seirei Mikatahara General Hospital, Tosei General Hospital, Tsuda Hospital and Yoshijima Hospital.

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TABLE 1 Subject characteristics

	Mean ± SD	Range
Age (years)	71.8 ± 5.7	55 - 86
FEV1 (L)	0.90 ± 0.4	0.32 - 2.30
FEV1 (% predicted)	33.9 ± 14.3	11.8 - 78.4
FVC (L)	2.3 ± 0.7	1.1 - 3.72
FEV1 / FVC (%)	39.5 ± 10.6	15.7 - 63.1
ISWT distance* (m)	346.8 ± 125.6	120 - 610
SGRQ activity	57.2 ± 21.6	6 - 92.5
SGRQ impact	32.9 ± 21.2	0 - 92.2
SGRQ symptoms	50.1 ± 22.1	8.8 - 100
SGRQ total	44.2 ± 19.3	4.5 - 90
Pilot 26-item questionnaire [†]	78.3 ± 21.6	17 - 104

^{*}The 56 subjects who were not receiving supplementary oxygen.

ISWT, Incremental Shuttle Walking Test; SGRQ, St. George's Respiratory Questionnaire.

[†]A pilot 26-item questionnaire previously generated by open-ended interview and by literature review.

TABLE 2 Relationships between scores on the Activity of Daily Living Dyspnea scale and Medical Research Council dyspnea grades, functional exercise capacity and health-related quality of life

ADL-D	MRC	ISWT		SG	RQ	
scale		distance [†]	activity	impact	symptoms	total
-0.79*						
0.67*	-0.59*					
-0.83*	0.72*	-0.57*				
-0.71*	0.68*	-0.46*	0.70*			
-0.54*	0.52*	-0.35*	0.63*	0.68*		
-0.79*	0.74*	-0.52*	0.86*	0.95*	0.79*	
	-0.79* 0.67* -0.83* -0.71* -0.54*	-0.79* 0.67* -0.59* -0.83* 0.72* -0.71* 0.68* -0.54* 0.52*	-0.79* -0.83* -0.72* -0.57* -0.71* -0.68* -0.46* -0.54* -0.52* -0.35*	-0.79* -0.83*	scale MRC distance† activity impact -0.79* 0.67* -0.59* -0.83* 0.72* -0.57* -0.71* 0.68* -0.46* 0.70* -0.54* 0.52* -0.35* 0.63* 0.68*	scale MRC distance† activity impact symptoms -0.79* 0.67* -0.59* -0.83* 0.72* -0.57* -0.71* 0.68* -0.46* 0.70* -0.54* 0.52* -0.35* 0.63* 0.68*

^{*}P < 0.001; †Data obtained in the 56 subjects who were not receiving supplementary oxygen.

ADL-D scale, the Activity of Daily Living Dyspnea scale; MRC, the Medical Research Council dyspnea grade; ISWT, Incremental Shuttle Walking Test; SGRQ, St. George's Respiratory Questionnaire.

FIGURE 1 The development process of the Activity of Daily Living Dyspnea scale.

[The pilot 26-item questionnaire]

walking on level ground washing feet

walking up stairs washing a towel or kitchen cloth by hand

walking uphill hanging the laundry up to dry

standing up from sitting position on the floor vacuuming the floor

walking inside the home sweeping the floor with a broom

straining to pass a bowel motion wiping a table putting on and taking off jacket wiping the floor

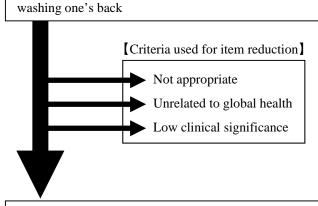
putting on and taking off trousers lifting a heavy object from the floor to a table

putting on and taking off socks hanging the futons up to dry

washing face taking an object from a high place

brushing teeth carrying a heavy object

washing hair bending over washing one's back shopping



The Activity of Daily Living Dyspnea scale (the items which were not eliminated)

FIGURE 2 Box plot showing relationship between the Activity of Daily Living Dyspnea scale (ADL-D scale) and the Medical Research Council dyspnea grade (MRC). Data are displayed as box-and-whisker plots. The box indicates the lower and upper quartiles and the central line is the median value. The horizontal lines at the ends of the vertical lines are the inner fence.

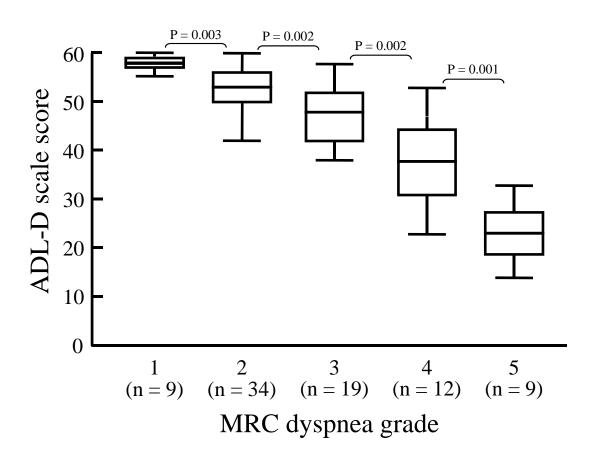
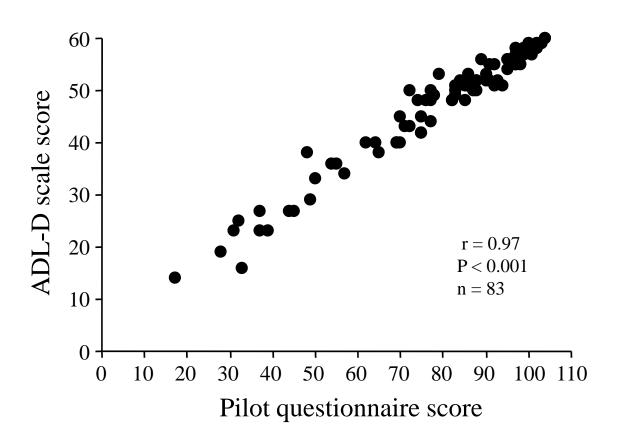


FIGURE 3 Scatterplot showing the relationship between scores obtained with the 15 item Activity of Daily Living Dyspnea scale (ADL-D scale) and the 26 item pilot questionnaire.



APPENDIX The Activity of Daily Living (ADL-D) scale containing the 15 items for assessing activity of daily living in patients with chronic obstructive pulmonary disease. Scale was originally developed in Japanese and translated into English.

The Activity of Daily Living Dyspnea scale and response sheet

NAME

DATE OF BIRTH

For each activity listed below, please rate your breathlessness on a scale between zero and four where 4 is not at all and 0 is maximally severe.

If you find some activities are not performed by you, please give your best estimate of breathlessness if you were to perform the task.

Your responses should be for an "average" day during the past week. $\label{eq:continuous}$

Please respond to all items.

	Not at all	Slight	Severe	Very severe	Maximally severe
walking on level ground	4	3	2	1	0
walking up stairs	4	3	2	1	0
walking uphill	4	3	2	1	0
walking inside the home	4	3	2	1	0
straining to pass a bowel motion	4	3	2	1	0
putting on and taking off jacket	4	3	2	1	0
putting on and taking off trousers	4	3	2	1	0
putting on and taking off socks	4	3	2	1	0
washing face	4	3	2	1	0
brushing teeth	4	3	2	1	0
washing hair	4	3	2	1	0
washing one's back	4	3	2	1	0
washing feet	4	3	2	1	0
bending over	4	3	2	1	0
shopping	4	3	2	1	0