



# Multicentre comparison of self-management in patients with COPD

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Shareable abstract (@ERSpublications)

This study compared patients' information needs from three institutions, highlighting real-world differences in information needs and the importance of assessing individual needs for self-management in COPD <https://bit.ly/3jlPbse>

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## Abstract

In patients with COPD, self-management plays an important role in disease management. Recently, self-management programmes have expanded patient education practices to include a variety of disease management techniques. We hypothesised that COPD patients have insufficient and/or different self-management needs according to institution. We compared information needs of patients between specialised clinics in Canada (SCC) and Japan and a hospital outpatient clinic in Japan (HCJ), all employing different self-management interventions.

This cross-sectional study evaluated patients' information needs for disease management using the Lung Information Needs Questionnaire (LINQ). Furthermore, we assessed pulmonary function tests, modified Medical Research Council (mMRC) dyspnoea scale and frequencies of hospitalisations and emergency visits.

The total number of patients was 183. Those attending SCC were younger ( $p=0.047$ ), with lower forced expiratory volume in 1 s % predicted ( $p<0.0001$ ), and scored higher on the mMRC dyspnoea scale. Total LINQ scores showed differences between institutions ( $p<0.0001$ ). There was no difference for the smoking domain; however, SCC recorded significantly lower information needs for all other domains ( $p<0.02$ ). No significant difference in emergency visits was seen between institutions, but HCJ recorded the highest rate of emergency visits, while SCC had significantly higher rates of hospitalisation ( $p=0.004$ ). Differences were seen for frequency and duration of education between institutions.

These results highlight the differences in information needs by institution and the importance of assessing individual needs. We believe, despite representing only one aspect of self-management, our findings reflect real-world circumstances, adding to the argument that self-management education should be structured, but flexible, to meet the changing needs of COPD patients.

## Introduction

COPD, characterised by airflow obstruction [1], is increasing in prevalence worldwide and is now the third leading cause of mortality [2]. Patients with poorly managed COPD require frequent hospitalisation, and the rates of mortality due to exacerbations have been reported to be approximately 11–24% [3]. Therefore, self-management is considered an integral component of the chronic care model of disease management [4].

Self-management programmes for COPD patients are primarily aimed at teaching the skills needed to control the disease and correct unhealthy behaviours to improve wellbeing [5]. Informing patients on how to avoid disease complications, such as exacerbations, has been thought to be the key to successful disease



management. However, recent literature has reported that traditional methods of self-management with the target of preventing exacerbations alone are outdated [6]. Instead, patients should be encouraged to acquire and apply self-management skills to enhance healthier behaviours in their daily lives.

Furthermore, self-management programmes can vary widely by institution. Strategies can range in time and scope from simple didactic instruction to more multifaceted self-management interventions. BOURBEAU *et al.* [7] reported that a comprehensive self-management education can provide information and skills that emphasise disease control through behaviour modification, thus increasing self-efficacy with the goal of improving clinical outcomes. Recently, self-management programmes have expanded their patient education practices to include a variety of disease management interventions such as smoking cessation, medication, exercise and nutrition, which is seen as critically important [6, 8].

We reported previously that an integrated education for COPD patients evaluated by the Lung Information Needs Questionnaire (LINQ) [9] improved patients' information needs, reduced disease symptoms and hospitalisations [3]. The LINQ was able to evaluate the knowledge that patients obtained through self-management programmes and could pinpoint the individual needs of the patient. For the present study, we hypothesise that patients with COPD might receive insufficient or different information for self-management programmes between facilities. The aim of this study is to compare information needs of patients with COPD between two specialised respiratory clinics and a general hospital outpatient clinic.

## Materials and methods

### Patient selection

This cross-sectional prospective observational multicentre study included patients across three institutions from Canada and Japan. Patients were recruited from the following institutions: 1) the Montreal Chest Institute of the McGill University Health Centre (specialised clinic, Canada (SCC)), Montreal, Canada, a specialised respiratory clinic with a well-established self-management education programme for patients with COPD; 2) the Respiratory Care Clinic (specialised clinic, Japan (SCJ)), Nippon Medical School, Tokyo, Japan, another specialised COPD clinic with a continuous education programme based on LINQ domains for the self-management of COPD; and 3) Tokai University Hospital (general hospital clinic, Japan (HCJ)), Kanagawa, Japan, a general hospital where patients visited the outpatient clinic for consultation regarding COPD, but without a standard or tailored self-management programme.

Inclusion criteria were as follows: patients aged >40 years with a formal diagnosis of COPD; a post-bronchodilator forced expiratory volume in 1 s ( $FEV_1$ ) of <80% predicted;  $FEV_1$ /forced vital capacity (FVC) <0.7; those who attended regularly scheduled appointments for  $\geq 6$  months at their primary institution; and a smoking history of  $\geq 10$  pack-years. Patients were excluded if they had a history of atopy or any apparent asthmatic features, a diagnosis of dementia or were illiterate in English and/or French (patients in Canada) or Japanese (patients in Japan).

All patients included in this study provided written informed consent and were able to withdraw at any time. This study, registered at Tokai University, was approved by the ethics committees of all participating institutions (approval number 12R-049).

### Outcome assessments

The LINQ was used to assess patients' knowledge of their disease at each setting. The LINQ is a self-administered questionnaire that measures the information needs of patients with COPD. Briefly, the LINQ is divided into six domains, and each domain is scored as follows: an understanding of COPD (0–4); the use of medications (0–5); the avoidance of exacerbations (0–6); risks of smoking (0–3); exercise (0–5); and nutrition (0–2). The sum of these scores is the total LINQ score (0–25). A higher score indicates a higher need for information on disease self-management. The total LINQ score provides an overview of the patient's information needs, and the individual domain scores identify specific needs.

### Outcome measurements

Pulmonary function parameters, including  $FEV_1$ , vital capacity and FVC, were measured according to the guidelines of the American Thoracic Society (ATS)/European Respiratory Society (ERS) [10] using equipment for lung function testing. The predicted value was calculated based on reference values from the ATS/ERS [10] (patients in Canada) and the Japanese Respiratory Society (JRS) [11] (patients in Japan).

COPD severity was assessed by spirometric classifications based on the ATS/ERS statement [8].

The severity of dyspnoea was evaluated using the modified Medical Research Council (mMRC) dyspnoea scale [12].

Exacerbations were self-reported from the previous year at the initial consultation for each setting. Exacerbations were defined as an increase in severity of the following respiratory symptoms: dyspnoea; cough and sputum volume; and sputum purulence that led to a change in medication or treatment, such as antibiotics or systematic corticosteroids, or admission to hospital [1]. Emergency visits and hospitalisations for the previous 12 months were self-reported by participants at initial interview.

### *Self-management programmes by institution*

#### *Specialised clinic, Canada*

SCC utilised the Living Well with COPD (LWWCOPD) self-management programme ([www.livingwellwithcopd.com](http://www.livingwellwithcopd.com)). Briefly, the LWWCOPD is an evidence-based self-management programme which is used extensively throughout Canada and other countries. The LWWCOPD was delivered by one 30-min education session per week, for 7–8 weeks, either one-to-one or in a group setting. An extensive range of teaching materials are available for health professionals and patients, and the education sessions range from basic information on COPD to integration of healthy behaviours and self-management strategies. LWWCOPD includes an action plan for acute exacerbation that is customised for each patient, including a contact list and a symptom-monitoring list for different situations.

#### *Specialised clinic, Japan*

Each patient received an individually tailored programme. Treatment and healthcare management plans were created for each patient's self-management needs, including an action plan for exacerbations. Education was delivered *via* monthly individual sessions with  $\geq 30$  min spent with each patient. All patients were provided with an education booklet based on the six domains of LINQ [13] which was used during each session. An action plan including instructions for exacerbation was provided to each patient. Education was conducted in an interactive style, with patients encouraged to ask questions about current or past sessions.

#### *General hospital clinic, Japan*

Patients visited the outpatient clinic for consultation once or twice a month regarding their disease symptoms and medications. During individual consultations, patients were asked about self-management techniques they may have been concerned about. Nurses instructed patients on self-management techniques for  $\geq 15$  min based on patient inquiries using third-party publicly accessible materials based on guidelines from the JRS [14]. Pulmonologists and nurses, at their own discretion, further prepared self-management materials for patients building on past consultation visits or when they believed there was a lack of knowledge. Advice, but no formal action plan, was used during consultations.

### *Statistical analysis*

We calculated the mean $\pm$ SD with categorical variables expressed as percentages. Comparison among multiple groups were assessed by ANOVA and Chi-squared test or Fisher's exact tests (for categorical variables). A p-value  $< 0.05$  was considered significant. Data were analysed using Statistical Package for the Social Sciences, version 25.0 for Windows (IBM SPSS, Chicago, IL, USA).

### *Results*

Patient characteristics for each institution are shown in table 1. The total number of patients was 183 (SCC n=45, SCJ n=105, HCJ n=33); 28 were female. SCC had the youngest patient population (SCC 69.0 years, SCJ 72.6 years, HCJ 72.9 years) ( $p=0.047$ ). Furthermore, SCC had lower FEV<sub>1</sub> values (SCC 35.3% pred, SCJ 68.9% pred, HCJ 60.1% pred) ( $p<0.0001$ ) and scored higher on the mMRC dyspnoea scale (SCC 2.87, SCJ 1.01, HCJ 1.39) ( $p<0.0001$ ).

COPD severity of patients is shown in figure 1. For the SCC, 20% of patients had moderate COPD, while 40% had each of severe and very severe COPD. There were no mild COPD patients at SCC. In contrast, at the SCJ, mild and moderate COPD patients comprised 71.4%, while severe COPD patients comprised 25.7% of the cohort and 3% of patients were very severe. For the HCJ, mild and moderate COPD patients made up 75.8% of the total, while 12.1% were severe and very severe COPD (four patients each).

The mean total LINQ scores showed significant differences between institutions ( $p<0.0001$ ) (SCC 3.91, SCJ 6.29, HCJ 9.79) (table 2). Although there were no differences in the smoking domain between groups, SCC recorded lower information needs for disease knowledge ( $p=0.013$ ), medications ( $p<0.0001$ ), avoidance of exacerbations ( $p<0.0001$ ), exercise ( $p=0.007$ ) and nutrition ( $p=0.014$ ) (table 2). When

TABLE 1 Patient characteristics

	Specialised clinic, Canada	Specialised clinic, Japan	General hospital clinic, Japan	p-value
Patients	45	105	33	
Age (years)	68.96±9.02	72.56±7.75	72.88±5.89	0.0474
Male/female	29/16	98/7	28/5	<0.0001
FVC (L)	2.16±0.77	3.18±0.70	2.79±0.79	<0.0001
FEV <sub>1</sub> (L)	0.95±0.42	1.67±0.65	2.06±3.28	<0.0001
FEV <sub>1</sub> % pred	35.31±14.64	68.88±25.23	60.14±22.32	<0.0001
mMRC dyspnoea scale	2.87±0.81	1.01±0.96	1.39±0.83	<0.0001

Data are presented as n or mean±SD, unless otherwise stated. FVC: forced vital capacity; FEV<sub>1</sub>: forced expiratory volume in 1 s; mMRC: modified Medical Research Council.

comparing institutions in Japan, SCJ patients revealed lower information needs than HCJ patients for disease knowledge, avoidance of exacerbations and exercise domains.

There was no significant difference in emergency visits for the previous year among institutions, but the HCJ recorded the highest rate of emergency visits. SCC had a significantly higher number of hospitalisations for the previous year when compared with Japanese institutions ( $p=0.0004$ ) (table 3).

The self-management education settings for each institution are shown in table 4. There were differences seen between medical systems and facilities between Canada and Japan. Whereas patients in Canada were treated by their primary care physicians, Japanese patients were free to choose between physicians and hospitals. All settings in this study were outpatient clinics, but educators and self-management interventions varied. The SCC included respiratory physicians, nurses, physiotherapists, respiratory therapists and a dietician, while the SCJ was staffed by respiratory physicians, nurses and a dietician. The HCJ included only respiratory physicians and nurses. Furthermore, there were differences in duration for education and frequency of visits between institutions. Patients attending the SCC spent 30 min per visit once a week, and those attending the SCJ spent 30 min per visit once a month, while those attending the HCJ were allotted 15 min per education session, once or twice a month.

## Discussion

This study compared the information needs of patients assessed using the LINQ from two specialised respiratory clinics and a general hospital outpatient clinic and found that self-management of COPD differed by institution. Those attending specialised COPD settings had a better understanding of their

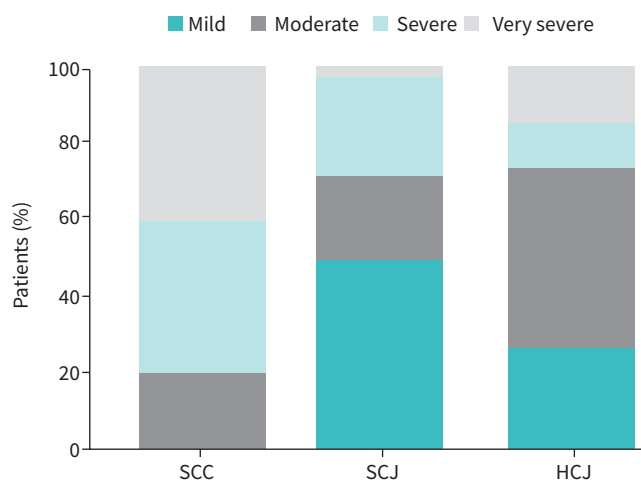


FIGURE 1 Severity of COPD in patients by institution. Patients attending the specialised clinic, Canada (SCC) were more severe than patients from the specialised clinic, Japan (SCJ) and the general hospital clinic, Japan (HCJ) ( $p<0.0001$ ).

TABLE 2 Lung Information Needs Questionnaire (LINQ) domain scores by institution

	Specialised clinic, Canada	Specialised clinic, Japan	General hospital clinic, Japan	p-value
<b>Patients</b>	45	105	33	
<b>LINQ domain</b>				
Disease knowledge (range 0–4)	0.86±0.84	1.12±0.66	1.60±1.20	0.0126
Medications (range 0–5)	0.27±0.54	0.48±0.81	0.79±1.34	<0.0001
Avoidance of exacerbations (range 0–6)	0.98±1.14	2.47±1.60	4.52±1.52	<0.0001
Smoking cessation (range 0–3)	0.16±0.37	0.04±0.19	0.12±0.42	0.091
Exercise (range 0–5)	1.02±0.94	1.18±0.84	1.91±1.35	0.0070
Nutrition (range 0–2)	0.62±0.83	1.00±0.39	0.85±0.76	0.0138
<b>LINQ total score (range 0–25)</b>	<b>3.91±2.63</b>	<b>6.29±2.63</b>	<b>9.79±3.67</b>	<b>&lt;0.0001</b>

Data are presented as n or mean±SD, unless otherwise stated.

disease and were better able to respond to exacerbations compared to those attending the general hospital. Although the specialised clinics in this study shared similarities in their structured self-management programmes and comprehensive approach, the SCC scored better on the LINQ, despite the SCJ programme being based on the LINQ. We believe this might be due to differences in disease severity that could have affected patient outcomes.

#### Information needs for self-management

Insufficient information in the self-management of COPD can lead to poor clinical outcomes. In this study, information needs were assessed using the LINQ, which has been proven to highlight areas of insufficient knowledge for self-management in COPD patients [3]. The LINQ, which is a self-administered, 16-item questionnaire has been shown to be effective at detecting the information needs of individuals and might have greater benefits for nonspecialised institutions without integrated self-management programmes. Since information needs and the number of emergency visits were highest for the HCJ compared with the specialised clinics, the LINQ could be considered a good starting point to assess the knowledge of each patient.

Self-management programmes used by specialised clinics provide comprehensive information to patients, but for general clinics without self-management programmes, it can be difficult to provide self-management information due to time and resource limitations. This was the case in the present study where the HCJ recorded higher information needs for all LINQ domains, except smoking cessation. It has been reported that patients who consulted their general practitioners were dissatisfied with the treatment options available to them [15], namely that they were limited to medicine use and smoking cessation rather than pulmonary rehabilitation or other aspects of self-management. In our study, LINQ domain scores were low for the smoking and medication domains for all settings, despite a significant difference seen for the medication domain. We consider that a reason for this could be that COPD patients might have enough information for smoking and medications, since these self-management components are now widely implemented as standard interventions in most medical settings.

Therefore, using LINQ in nonspecialised settings to objectively assess various gaps in self-management information for COPD might contribute to more efficient and individualised self-management interventions or assist in the decision to refer patients to more specialised COPD settings.

TABLE 3 Number of emergency visits and hospitalisations by institution

	Specialised clinic, Canada	Specialised clinic, Japan	General hospital clinic, Japan	p-value
<b>Patients</b>	45	105	33	
<b>ER visits per year</b>	0.53±0.81	0.47±0.83	0.91±1.63	0.3331
<b>Hospitalisations per year</b>	1.07±1.89	0.07±0.35	0.67±1.37	0.0004

Data are presented as n or mean±SD, unless otherwise stated. ER: emergency room.

TABLE 4 Comparison of self-management settings

	Specialised clinic, Canada	Specialised clinic, Japan	General hospital clinic, Japan
Consultation	Referral	Free access	Free access
Setting	Clinic, outpatient	Clinic, outpatient	Hospital, clinic, outpatient
Educators	Physician, nurse, physiotherapist, respiratory therapist, dietician	Physician, nurse, dietician	Physician, nurse
Pulmonary rehabilitation	Yes	No	No
Education programme	LWWCOPD	LINQ	No
Action plan	Yes	Yes	No
Education	Every visit	Every visit	When deemed necessary
Duration	30 min	30 min	15 min

LWWCOPD: Living Well with COPD; LINQ: Lung Information Needs Questionnaire.

### *Disease severity and hospitalisation rates*

Exacerbations of COPD develop from an acute worsening of a patient's condition from a stable state which results in a change in medications or hospitalisations. It has been reported that the number of hospitalisations per year is positively correlated to the degree of COPD severity [16], which was similar to the present study. Despite having lower information needs, the SCC patients had significantly higher rates of hospitalisation and dyspnoea, which is probably due to higher disease severity.

The present study revealed that patients at Japanese institutions were older, predominantly male, and had less severe COPD and lower mMRC dyspnoea scale scores. Since this study was observational in design, patients were not controlled for age or disease severity. However, these findings are similar to a literature review by *ISHII et al.* [17], which reported that patients from Japan had less severe COPD, less dyspnoea and reported lower exacerbation rates than patients from other countries. Although there was no definitive reason as to why these findings are constantly reported, it is considered that extrinsic factors such as lifestyle or better access to healthcare may have contributed to these results.

### *Integrated self-management*

The American College of Chest Physicians and Canadian Thoracic Society guideline on the prevention of acute exacerbations of COPD states that specially trained staff for education and case management is needed to supervise educational interventions [18].

In our study, we noted a difference in medical staff between specialised clinics and the general hospital outpatient clinic. There were overlaps seen for medical workers at each specialised clinic which employed multidisciplinary staff members, whereas the general hospital was staffed with only physicians and nurses. Although this study included patients who received consultations for  $\geq 6$  months prior to the evaluation by LINQ, it did not investigate the total duration or quality of education patients received. Therefore, the absence of a multidisciplinary medical team may have negatively affected the HCLJ patients' knowledge on a variety of disease management techniques.

However, it is ultimately the decision of each institution to identify optimal care for their patients according to the resources of each institution. For the SCC, as patients had more severe COPD, their comprehensive approach to self-management, including pulmonary rehabilitation, may have contributed to better adherence and retained education than for the Japanese settings. For the SCJ, since patients had predominantly stable COPD, less integrated care may be more beneficial.

### *Limitations*

There were several limitations to this study. Although we compared self-management in patients across three facilities, the sample size, gender and age of patients differed greatly between settings. However, this is in line with the aforementioned review in which patients in Japan are older and predominantly male. Moreover, disease severity for the SCC was much higher than for the Japanese population. This might be explained by the difference in the referral system used in Canadian settings whereby stable patients may have been treated longer by their primary care physicians rather than independently seeking out specialised care, although further study is needed to confirm these differences.

Another limitation could be the underlying factors for exacerbations. We did not assess comorbidities or body mass index in this study and these factors may have contributed to the higher hospitalisation rate for the SCC. Furthermore, we found that frequency of visits and the time self-management education was delivered varied widely between settings, especially between specialised and nonspecialised clinics. Many studies have tried to identify the most suitable self-management programme; however, self-management with an emphasis on individual patient's needs over the course of their disease might be considered the most beneficial to the patient, regardless of age, gender or disease severity.

Furthermore, motivation may have been a factor in patients who visited specialised clinics to those visiting the general hospital. Although motivation was not assessed in this study, there has been growing interest in the assessment of motivation in self-management of COPD. Therefore, future studies are needed to assess the outcomes in motivation for self-management.

### Conclusion

This study showed that patients' information needs for the self-management of COPD differed by institution, and that a formal, individualised self-management education was beneficial in retaining or enhancing the patient's self-management information, and in the avoidance of exacerbations. We believe that our findings, although only one aspect of self-management, reflect real-world circumstances adding to the argument that self-management education should be structured, but flexible, to meet the changing needs of COPD patients.

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