# **Early View**

Original article

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# Multi-Centre Comparison of Self-Management in Patients with COPD

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# Take home message:

SM programmes include various disease management techniques. We compared patients' information needs from three institutions, highlighting real-world differences in information needs and the importance of assessing individual needs for SM interventions.

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#### Abstract

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

This cross-sectional study evaluated patients' information needs for disease management using the lung information needs questionnaire (LINQ). Further, we assessed pulmonary function tests, modified Medical Research Council dyspnoea scale (MMRC), and frequencies of hospitalisations and emergency visits.

The total number of patients was 183. SCC were younger (p=0.047), with lower FEV<sub>1</sub>%predicted (p<0.0001) and scored higher on MMRC. Total LINQ scores showed differences among 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 among 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 our findings, although only one aspect of SM, reflect real-world circumstances adding to the argument that an SM education should be structured but flexible to meet the changing needs of COPD patients.

Key words: COPD; Hospitalisation; Lung information needs questionnaire; Patient education; Self-management.

# Introduction

Chronic obstructive pulmonary disease (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 (SM) is considered an integral component of the chronic care model of disease management [4].

SM programmes for COPD patients are primarily aimed at teaching the skills needed to control their disease and correct unhealthy behaviours to improve well-being [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 SM with the target of preventing exacerbations alone are outdated [6]. Instead, patients should be encouraged to acquire and apply SM skills to enhance healthier behaviours in their daily lives.

SM programmes can also vary widely by institution. Strategies can range in time and scope from simple didactic instruction, to more multi-faceted SM interventions. Bourbeau et al. reported that a comprehensive SM education can provide information and skills that emphasise disease control though behaviour modification, thus increasing self-efficacy with the goal of improving clinical outcomes [7]. Recently, SM 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 previously reported 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 SM programmes and could pinpoint the individual needs of the patient. For this present study, we hypothesise that patients with COPD might have insufficient or different information for SM 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 multi-centre 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 (SCC), Montreal, Canada, a specialised respiratory clinic with a well-established SM education programme for patients with COPD; 2) the Respiratory Care Clinic (SCJ), Nippon Medical School, Tokyo, Japan, also a specialised COPD clinic with a continuous education programme based on LINQ domains for the SM of COPD; and 3) Tokai University Hospital (HCJ), Kanagawa, Japan, a general hospital where patients visited the outpatient clinic for consultation regarding COPD, but without a standard or tailored SM programme.

Inclusion criteria were as follows: patients over 40 years of age with a formal diagnosis of COPD; a post-bronchodilator forced expiratory volume in 1 s (FEV<sub>1</sub>) of <80% predicted; an FEV<sub>1</sub>/ forced vital capacity (FVC) < 0.7; those who attended regularly scheduled appointments for at least 6 months at their primary institution; and a smoking history of at least 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 for patients in Canada or Japanese for 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 SM. 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<sub>1</sub>, vital capacity (VC) and FVC, were measured according to the guidelines of the American Thoracic Society/European Respiratory Society (ATS/ERS) [10] using equipment for lung function testing. The predicted value was calculated based on reference values from the ATS/ERS for patients in Canada [10], and the Japanese Respiratory Society (JRS) for patients in Japan [11].

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

The severity of dyspnoea was evaluated by the modified Medical Research Council Dyspnoea Scale (MMRC) [12].

Exacerbations were self-reported from the previous year at 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 were also self-reported by participants at initial interview for the previous 12 months.

Self-management programmes by institution

Specialised Clinic, Canada (SCC)

SCC utilised the Living Well with COPD (LWWCOPD) SM programme (www.livingwellwithcopd.com). Briefly, the LWWCOPD [13] is an evidence-based SM programme which is used extensively throughout Canada and select countries. The

LWWCOPD was delivered by one 30-minute education session per week, for 7 to 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 SM 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 [13].

#### Specialised Clinic, Japan (SCJ)

Each patient received an individually tailored programme. Treatment and health care management plans were created for each patient's SM needs, including an action plan for exacerbations. Education was delivered via monthly individual sessions with at least 30 minutes spent with each patient. All patients were provided with an education booklet based on the six domains of LINQ [14] that was used during each session (Comprehensive respiratory care using the LINQ). 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 (HCJ)

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 SM techniques they may be concerned about. Nurses instructed patients on SM techniques for at least 15 minutes based on patient inquires using third

party publicly accessible materials based on guidelines from the JRS [15]. Pulmonologists and nurses, at their own discretion, further prepared SM 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 and standard deviation (SD) with categorical variables expressed as percentages. Comparison among multiple groups were assessed by one-way analysis of variance (ANOVA) and Chi-square 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 Inc., Chicago, Illinois, U.S.A.).

# Results

Patients' characteristics for each institution are shown in **Table 1**. The total number of patients was 183 (SCC: 45, SCJ: 105, HCJ: 33), 28 were female. SCC had the youngest patient population (SCC: 69.0y, SCJ: 72.6y, HCJ: 72.9y), (p=0.047). Furthermore, SCC had lower FEV<sub>1</sub>%predicted (SCC: 35.3%, SCJ: 68.9%, HCJ: 60.1%), (p<0.0001) and scored higher on MMRC (SCC: 2.87; SCJ: 1.01; HCJ: 1.39), (p<0.0001).

COPD severity of patients among institutions are shown in Figure 1. For the SCC, patients with moderate COPD were 20%, while severe and very severe patients were 40%, respectively. There were no mild COPD patients for SCC. On the other hand, for the SCJ, mild and moderate COPD patients consisted of 71.4%, while severe COPD

patients consisted of 25.7% and very severe were 3% of all patients. For the HCJ, mild and moderate COPD patients made up 75.8% of the total, while severe and very severe were 12.1% (4 patients each), respectively.

The mean total LINQ scores showed significant differences among 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 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 SM education settings for each institution are shown in **Table 4**. There were differences seen between medical systems and facilities between Canada and Japan. Whereby patients in Canada were treated by their primary care physicians, Japanese patients were free to choose among physicians and hospitals. All settings in this study were outpatient clinics but educators and SM interventions varied. The SCC consisted of respiratory physicians, nurses, physiotherapists, respiratory therapist, and a dietician, while the SCJ was staffed with 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. The SCC, once a week, and SCJ, once a month, each spent 30 minutes per visit, respectively, while the HCJ, once or twice a month, allotted 15 minutes per education session.

#### Discussion

This study compared the information needs of patients assessed by the LINQ from two specialised respiratory clinics and a general hospital outpatient clinic and found that SM of COPD differed by institution. Those attending specialised COPD settings had both a better understanding of their disease and were better able to respond to exacerbations compared to the general hospital. Although the specialised clinics in this study shared similarities in their structured SM 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 (SM)

Insufficient information in the SM of COPD can cause poor clinical outcomes. In this study, information needs were assessed using the LINQ which has been proven to highlight areas of insufficient knowledge for SM 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 to nonspecialised institutions without integrated SM 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.

SM programmes used by specialised clinics provide comprehensive information to patients, but for general clinics without SM programmes, it can be difficult to provide various SM 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, with exception to smoking cessation. It has been reported that patients who consulted their general practitioners were dissatisfied with the treatment options available to them [16]. Namely, that they were limited to medicine use and smoking cessation rather that 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 a reason for this could be that COPD patients might have enough information for smoking and medications, since these SM components are now widely implemented as standard interventions in most medical settings.

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

#### Disease severity and hospitalization rates

Exacerbations for COPD develop from an acute worsening of a patient's condition from a stable state which results in a change in medications or hospitalizations. It has been reported that the number of hospitalizations per year was positively correlated to the degree of COPD severity [17], 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 likely due to higher disease severity.

The present study revealed patients at Japanese institutions were older, predominantly male, and had less severe COPD and lower MMRC 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. which reported that patients from Japan had less severe COPD, less dyspnoea and reported lower exacerbation rates than patients from other countries [18]. 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 health care 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 a specially trained staff for education and case management is needed to supervise educational interventions [19]. 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 multi-disciplinary staff members, whereas the general hospital was staffed with only physicians and nurses. Although this study included patients who received consultations for at least six 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 multi-disciplinary medical team may have negatively affected the HCJ 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 by the resources of each institution. For the SCC, as patients were more severe, their comprehensive approach to SM, including pulmonary rehabilitation, may have contributed to better adherence and retained education than for the Japanese settings. For the SCJ, since patients were predominantly stable with their COPD, less integrated care may be more beneficial.

#### Limitations

There were several limitations to this study. Although we compared SM in patients across three facilities, sample size, gender and the age of patients differed greatly between settings. However, this is in line with the aforementioned review where patients in Japan are older and predominately 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 more study is needed to confirm

#### these differences.

Another limitation could be the underlying factors for exacerbations. We did not assess co-morbidities or body mass index in this study and these factors may have contributed to the higher hospitalisation rate for the SCC. Further, we found that frequency of visits and the time SM education was delivered varied widely between settings, especially between specialised and nonspecialised clinics. Many studies have tried to identify the most suitable SM programme; however, SM 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 SM of COPD. Therefore, future studies are needed to assess the outcomes in motivation for SM.

#### Conclusion

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

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Table 1 Patient characteristics

	SCC n=45	SCJ n=105	HCJ n=33	p-value
Age (y)	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
$FEV_1$ (L)	0.95 (0.42)	1.67 (0.65)	2.06 (3.28)	< 0.0001
FEV <sub>1</sub> , % predict (%)	35.31 (14.64)	68.88 (25.23)	60.14 (22.32)	< 0.0001
MMRC	2.87 (0.81)	1.01 (0.96)	1.39 (0.83)	< 0.0001

Mean (SD)

SCC: specialised clinic in Canada; SCJ: specialised clinic in Japan; HCJ: general hospital clinic in Japan; FVC: forced vital capacity; FEV1: forced expiratory volume in 1 second; MMRC: modified Medical Research Council dyspnoea scale.

Table 2 The LINQ domain scores by institution

	SCC n=45	SCJ n=105	HCJ n=33	p-value
LINQ domain				
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
LINQ total score (range: 0 - 25)	3.91 (2.63)	6.29 (2.63)	9.79 (3.67)	<0.0001

Mean (SD)

SCC: specialised clinic in Canada; SCJ: specialised clinic in Japan; HCJ: general hospital clinic in Japan; LINQ: lung information needs questionnaire.

Table 3 Number of emergency visits and hospitalizations by institution

_	SCC n=45	SCJ n=105	HCJ n=33	p-value
ER visits / year	0.53 (0.81)	0.47 (0.83)	0.91 (1.63)	0.3331
Hospitalization	1.07 (1.89)	0.07 (0.35)	0.67 (1.37)	0.0004

Mean (SD)

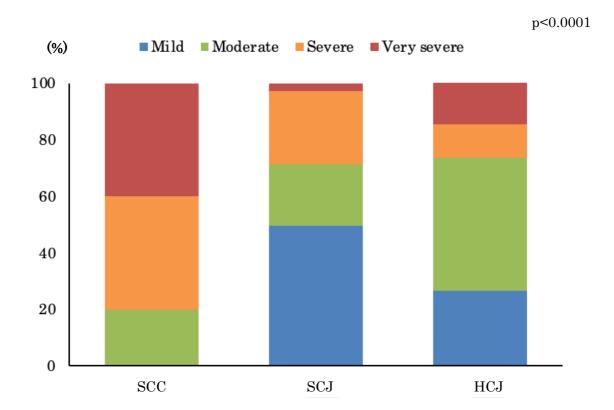
SCC: specialised clinic in Canada; SCJ: specialised clinic in Japan; HCJ: General hospital clinic in Japan; ER: emergency room.

Table 4 Comparison of self-management settings

	SCC	SCJ	HCJ
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

SCC: specialised clinic in Canada; SCJ: specialised clinic in Japan; HCJ: general hospital clinic in Japan.

Figure 1 Severity of COPD in patients by institution



Patients attending the specialised clinic in Canada (SCC) were more severe than patients from the specialised clinic in Japan (SCJ) and the general hospital clinic Japan (HCJ) (p<0.0001).