



Self-care approaches to managing chronic obstructive pulmonary disease: A provincial survey

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Summary

Background: Chronic obstructive pulmonary disease (COPD) is a common chronic respiratory condition associated with considerable personal and social burden yet little is known about how patients manage their condition.

Purpose: The purpose of this study was to identify, from the perspective of individuals living with COPD, their management approaches.

Methods: A mailed survey was conducted with individuals living in Ontario with physician confirmed COPD who experienced daily respiratory symptoms. Potential participants were identified through existing databases. Questionnaire development was based on focus groups and pilot testing.

Results: Completed questionnaires were received from 353 of the 452 eligible participants, representing a 78% response rate. The mean age of responders was 68 ± 12 years (sd) with 52% male, 85% ex-smokers, 52% with moderate COPD (self-report) and 52% treated by a family physician. Common strategies used by participants included inhaled bronchodilators (100%), annual influenza vaccination (90%), aerobic types of activity (75%), regular physician visits (72%), breathing exercises (69%) and inhaled steroids (67%). Forty-four percent of participants had scores indicative of depression. Participants (68%) reported using a shared decision-making model for management decisions and were satisfied with their interactions with the health care team (physician and non-physician).

Conclusion: Most individuals with COPD use several strategies to manage their disease. Health care professionals have an important role in ensuring that evidence-based guidelines for COPD are translated to patients.

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Introduction

Chronic obstructive pulmonary disease (COPD) is a leading cause of morbidity and mortality worldwide, and results in profound economic and social burden.¹ In Canada, COPD has a 6% prevalence rate that is continuing to increase and is the fourth and seventh leading cause of death in men and women, respectively.²

A comprehensive management plan for COPD includes smoking cessation, pharmacotherapy, immunization, long-term oxygen use, education, pulmonary rehabilitation, ventilatory support, and nutrition.^{3–5} In COPD, similar to other chronic diseases, day-to-day responsibilities for management fall heavily on patients and families. Self-care implies monitoring symptoms, implementing treatment regimens, maintaining a healthy lifestyle, and coping with and managing the impact of illness on daily functioning, emotions and relationships. Successful management of COPD depends on patients and their health care providers acknowledging the importance of shared responsibility for disease management with each party contributing unique expertise.

There is consensus among experts that patient education is a vital part of COPD management.^{3,5} In the asthma literature, studies exist demonstrating the positive impact of self-management on the personal, economic, and social burden of asthma.^{6,7} However, studies on the role of self-management in COPD are inconsistent. In a Cochrane review,⁸ comparing COPD self-management education programs to usual care, there were no improvements observed for hospital admissions, emergency room visits, days lost from work and lung function. In contrast, Bourbeau and colleagues⁹ observed that a COPD self-management program resulted in decreased health care utilization and improved health status.

There are several potential reasons for the conflicting findings. It is not sufficient to simply teach individuals with COPD about the pathology and medications used; there are many skills to develop and barriers to overcome before these skills and knowledge can be applied in everyday life.¹⁰ To date, no published studies have explored issues that influence the use of concurrent components of therapy such as immunization, exercise, medications, oxygen therapy, and follow-up appointments. Using focus groups, we identified several factors that influenced self-care including self-efficacy, mood, and barriers and enablers to using the self-care activity.¹⁰ The current study builds on our earlier work and involved conducting a survey among individuals with COPD. The primary

purpose of the study was to investigate, from the perspective of individuals with COPD, the use of interventions/strategies for managing the disease and how their use is influenced.

Methods

Design

The study received ethics approval from the University of Toronto. The survey followed Dillman's protocol for mailed surveys, which includes the following steps: (1) a pre-survey letter was sent to all potential participants informing them that the survey will arrive in approximately 1 week; (2) the questionnaire was mailed a week later; (3) 2-week reminders were sent out to non-respondents; and (4) at 5 and 9 weeks following the original questionnaire mailing, a reminder letter and an additional copy of the questionnaire were sent to non-respondents.¹¹ In accordance with Dillman's protocol, all letters were personalized, signed by the investigators using a ballpoint pen, mailed with first class postage stamps, and included a pre-addressed first class postage paid envelope for returning the questionnaire.

Sample

Participants were recruited from databases of individuals with COPD residing in Ontario who contacted toll-free telephone lines for information about the condition. Eligibility criteria included: (a) having a physician confirmed diagnosis of COPD; (b) experiencing daily respiratory symptoms; and (c) an ability to read English. All individuals in the databases ($n = 521$) were sent a letter of invitation to participate.

Questionnaire

Development of the questionnaire was based on previous work¹⁰ and took 20–30 min to complete. It consisted of four sections. "Introduction", the largest section, explored the individual's self-care activities, identified the helpfulness of activities and enablers and barriers to performing the activities. Individuals were asked about 12 activities: breathing exercises, exercises (walking, etc.), strengthening exercises, inhaled short-acting bronchodilators, inhaled long-acting bronchodilators, inhaled corticosteroids, inhaled combination (long-acting β agonists and corticosteroid) therapy, oxygen, flu shots, follow-up visits with a doctor and

other health professionals, and the use of complementary therapies. The level of helpfulness was determined through use of a 5-point Likert scale. The respondent's level of confidence or self-efficacy for the activities was assessed using a 5-point Likert scale.

Section 2 used The Center for Epidemiologic Studies Depression Scale (CES-D) to identify the risk of depression. It is a 20-item self-administered questionnaire with scores ranging from 0 to 60; scores of 16 or more are suggestive of depression and has been used in individuals with COPD.^{12,13}

The third section asked individuals to indicate their level of involvement in management decisions and perceptions of the quality of interactions with their health care team.^{14,15} The last section, Section 4, collected demographic and respiratory health-related information.

Data analysis

A descriptive summary and frequency analysis was performed for all questions. Where appropriate, means and standard deviations (*sd*) are reported. Correlation coefficients were used to examine the possibility of relationships between self-efficacy and effectiveness and frequency of use of self-care activities. Relationships could only be explored for strategies relating to exercise because little variance existed for the use of medications (>90% reported regular daily use).

Results

Of the 521 letters of invitation sent to potential participants, 69 individuals were ineligible (died, was a health care professional or a family member, or wrong address). Of the remaining 452 potential participants, 353 questionnaires were returned representing a response rate of 78%.

The average participant was retired, 68 years of age, and an ex-smoker with a self-report of moderate COPD. Most participants were followed solely by a family physician (52%) and had not attended a pulmonary rehabilitation program (80%). See Table 1.

Self-care approaches

The study assessed the use of several therapeutic self-care strategies to manage COPD (Fig. 1). The most frequently reported (90%) self-care strategy was to receive an annual influenza vaccination. All individuals had an inhaled bronchodilator but the

Table 1 Characteristics of participants (*n* = 353).

Characteristic	% (<i>n</i>)
Age (mean \pm <i>sd</i>)	68 \pm 12 years
Male	52 (184)
Marital status	
Married or equivalent	62 (219)
Widowed	18 (64)
Divorced	14 (49)
Never married	6 (21)
Educational level greater than high school diploma	22 (78)
Smoking status	
Ex-smoker	85 (300)
Length of time as ex-smoker (mean \pm <i>sd</i>)	11 \pm 10 years
Current smoker	15 (53)
COPD severity (self-report)	
Mild	18 (63)
Moderate	52 (184)
Severe	30 (106)
Primary medical provider	
Family physician	52 (184)
Respirologist	26 (92)
Both	14 (49)
Ever attended a pulmonary rehabilitation program	20 (71)
Ever required	
Emergency department visit for COPD	51 (180)
Hospitalization for COPD	38 (134)
Medication	
Inhaled steroid (IS)	67 (238)
Short-acting β agonist	67 (236)
Long-acting β agonist (LABA)	55 (194)
Short-acting anticholinergic	41 (145)
Long-acting anticholinergic	34 (120)

type or classification (short vs. long acting; β_2 vs. anticholinergic) varied. Approximately 70% of participants used an aerobic form of exercise (walking, bicycling), follow-up medical appointments, and breathing exercises to manage COPD. Strengthening exercises, complementary therapies, visits with allied health care professionals, and oxygen were strategies least commonly used. Approximately one-third of participants used complimentary therapies with the most common being the use of vitamins, herbal preparations, and Tai Chi.

The frequency of use for the various strategies was assessed. Nearly half of participants (44%) saw

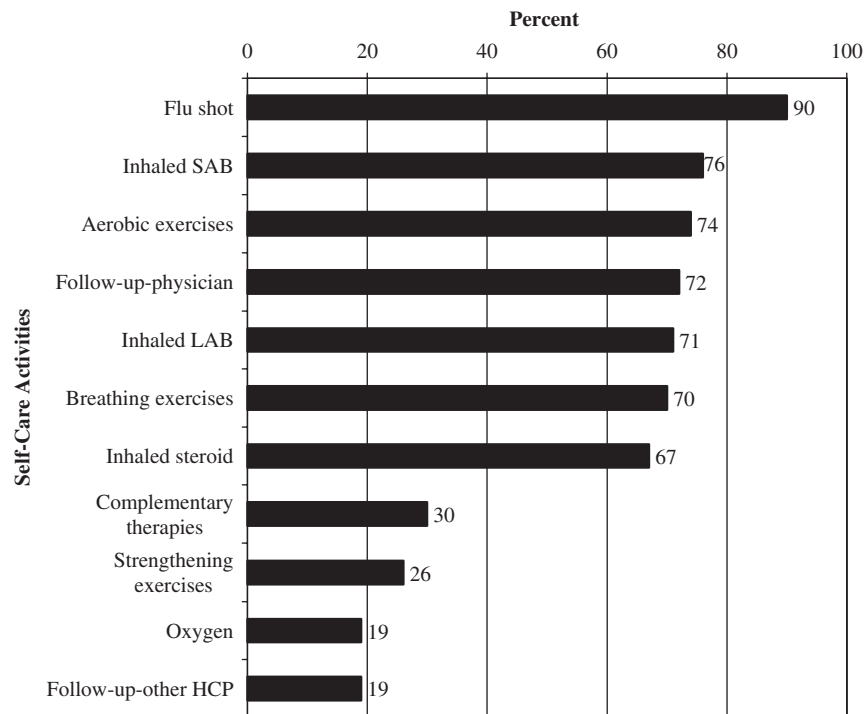


Figure 1 Self-care activities used by patients with COPD: a frequency distribution. SAB: short-acting bronchodilator (β_2 agonist or ipratropium bromide). LAB: long-acting bronchodilator (long-acting β_2 agonist or tiotropium).

their physician at least every 3 months for COPD and 81% saw their physician at least twice a year for COPD. Aerobic and strengthening exercises were performed at least three times a week for the majority of participants (72% and 58%, respectively). Breathing exercises were performed daily by 51% of participants. Over 90% used their medications daily.

The helpfulness of the various activities was also explored. Activities reported to be helpful included oxygen (90%), flu shots (81%), long-acting bronchodilators (79%), short-acting bronchodilators (76%), medical appointments (63%), and breathing exercises (60%). Weak but significant relationships were observed between usefulness and frequency of use for breathing exercises ($r = 0.22$, $P < 0.001$), aerobic exercise ($r = 0.20$, $P < 0.05$), and strengthening exercises ($r = 0.32$, $P < 0.001$).

Several barriers, motivators, and enablers were reported to influence the use of COPD self-care strategies (Tables 2 and 3). Across all self-care activities common barriers identified included not knowing about the activity or not having it recommended, changes in daily activity (vacation, guests, appointments), and mood. However, barriers tended to vary according to the type of self-care activity. Specific barriers to the use of oxygen therapy were the aesthetics of the apparatus (13%) and being too cumbersome (20%).

The most common motivators were: feeling better as a result of the strategy (71%), a fear of getting worse if the strategy was not used (64%), their own self-determination to perform the activity (57%), and that their health care provider told them to do it (52%). Reasons for seeking follow-up medical care were to have an opportunity to communicate (66%) and to stay informed of the latest therapies (61%).

Participants felt confident in their ability to perform self-care activities. Respondents felt most confident administering medications; 96% felt confident they could administer their oxygen correctly and 88% felt confident in using inhalers correctly. Weak relationships were observed between self-efficacy and exercise frequency. Specifically, as individuals felt more confident in their ability to perform breathing exercises ($r = 0.18$, $P < 0.05$), strengthening exercises ($r = 0.18$, $P < 0.05$), and aerobic forms of exercise ($r = 0.22$, $P < 0.05$) they increased the use of the activity.

Emotional health

A significant proportion (44%) of respondents had scores indicative of depression as measured by the CES-D. It was hypothesized that gender, severity and intrusiveness (bothersome) of COPD, and social

Table 2 Common barriers to self-care activities according to activity ($n = 353$).

	% (n)
Breathing exercises	
Low energy level	42 (148)
Don't know how/not suggested	38 (134)
Changes in normal routine (holiday, guests, appointments)	28 (99)
Exercise (aerobic and strengthening)*	Mean of % \pm SD
Low energy level	40 \pm 10
Physically unable to do	36 \pm 2
Don't know how/not suggested	35 \pm 12
Inhaled bronchodilators (short and long acting)*	Mean of % \pm SD
Forget	40 \pm 0
Changes in normal routine (holiday, guests, appointments)	20 \pm 2
Oxygen	% (n)
Too cumbersome	20 (71)
Don't like the way it looks	15 (53)
Flu shot	% (n)
Miss flu clinic	10 (35)
Ineffective	7 (25)
Regularly scheduled follow-up medical appointments	% (n)
Weather	19 (67)
Difficult to get an appointment	16 (56)
Not recommended	15 (53)

*Indicates two activities combined to provide mean and SD.

isolation may play a role in depression. Secondary analysis revealed that individuals with scores suggestive of depression were more likely to be female (54% vs. 39%, $P < 0.001$), be divorced or never married ($P = 0.002$), and report increased severity and bothersome COPD ($P < 0.0001$).

Involvement in management decisions and satisfaction with health care encounters

Most individuals (58%) indicated that they preferred some type of shared decision-making model but the proportion of sharing varied between the physician and patient. In contrast, 29% reported that they preferred the physician to be the sole decision maker and 13% preferred themselves to be the sole decision maker for COPD management decisions.

The majority of participants reported that their doctor was accessible (83%) and that they had trust and confidence in their physician (84%). Several characteristics of the patient clinician encounter were explored (see Table 4). Most participants

Table 3 Common motivators for performing self-care activities according to activity.

	% (n)
Breathing exercises ($n = 247$)	
Fear of getting worse	68 (168)
Feel better	61 (151)
Self-determination	53 (131)
Exercise (aerobic and strengthening) ^a	Mean \pm SD
Feel better	64 \pm 2
Self-determination	58 \pm 1
Fear of getting worse	52 \pm 1
Inhaled bronchodilators (short and long acting) and oxygen ($n = 353$) ^a	Mean \pm SD
Symptoms are better controlled	73 \pm 1
Advice of health professional	58 \pm 5
Feel better	52 \pm 8
Flu shot ($n = 318$)	% (n)
Advice of health professional	76 (242)
Fewer infections	58 (185)
Fear of getting worse	41 (130)
Follow-up medical appointments ($n = 255$)	% (n)
Opportunity to communicate	66 (169)
Receive advice and suggestions	65 (166)
Learn about new therapies	61 (156)

^aIndicates two activities combined to provide mean and SD.

(over 80%) felt they were being listened to, could ask questions and receive answers they could understand but had concerns they wanted to discuss but did not get a chance.

Discussion

The current study indicates that most individuals with COPD use a combination of self-care strategies to manage their condition that include an annual influenza vaccination, inhaled short- and long-acting bronchodilators, inhaled corticosteroids, follow-up medical appointments, and breathing exercises. Several barriers and enablers to self-care existed. The most common motivators were a desire to feel better, a fear of getting worse, and being told to perform the activity by a health care professional. Respondents relied on their self-determination and personal discipline to manage COPD. Common barriers identified included a lack of knowledge, not having the activity recommended by a health care professional, a low energy level or inability to perform the activity, changes in

Table 4 Characteristics of the patient–clinician interaction according to profession.

Characteristic of clinician–patient encounter (<i>n</i> = 353)	Physician % (<i>n</i>)	Allied health % (<i>n</i>)
Listened to you and your family	91 (321)	90 (318)
Involved in decisions as much as wanted	81 (286)	75 (265)
Received as much information as wanted about COPD	70 (247)	76 (268)
Explained tests and treatments in an understandable way	80 (282)	81 (286)
Able to ask questions	91 (321)	94 (332)
Got questions answered in an understandable way	81 (287)	84 (297)
Had concerns that did not get to discuss	40 (141)	24 (84)
Asked/discussed how COPD affects life	24 (85)	35 (124)
Explained what to do if condition worsens	59 (208)	57 (201)

normal routine (vacation, visitors, appointments), and mood. A considerable proportion of respondents had scores suggestive of depression (44%). Participants preferred some level of shared care in managing COPD and were satisfied with their interactions with the health care team.

Our observation that 44% of individuals with COPD are affected by depression is consistent with the literature.^{15–17} Secondary analysis in the current study revealed observations consistent with earlier work, indicating that individuals with scores suggestive of depression were more likely to have increased disease severity and bothersome COPD, to be females and living alone.^{12,17–19} Kunik and colleagues¹⁸ revealed that few patients with breathing problems are treated with antidepressants. In our study, less than 5% reported using an antidepressant. The current study in conjunction with existing literature suggests that depression is a significant issue for individuals with COPD.^{12,16–19}

Data from this study provide an indicator of success of the translation and implementation of the Canadian COPD guidelines.³ The current study observed that 100% of participants had an inhaled bronchodilator (β_2 agonist and/or anticholinergic), which is consistent with the Canadian guidelines. However, when the breakdown of bronchodilators was examined, 24% of participants did not have a short-acting bronchodilator but instead relied only on a long-acting inhaled bronchodilator (β_2 agonist and/or anticholinergic). The Canadian guidelines recommend using short-acting bronchodilators on an as-needed basis for immediate relief of symptoms. However, most patients reported that they do not adjust their use of short-acting bronchodilators based on symptoms, which suggests an area for future education and clarification for patients. The current study also assessed the use of inhaled corticosteroids. Inhaled corticosteroids are not identified as first line therapy because they do not slow the decline in lung function. They are, however, recommended for patients who have

frequent exacerbations or moderate to severe defects in lung function. Our study suggests that approximately two-thirds of participants were using inhaled corticosteroids on a regular daily basis and this might be construed as over use. The role of inhaled steroids for the treatment of COPD has been controversial and apparently still represents an area of confusion for patients and clinicians.

Pulmonary rehabilitation has demonstrated efficacy and is known to assist with relieving dyspnea, enhancing exercise tolerance, and improving quality of life.⁴ Despite our recognition of the benefits of pulmonary rehabilitation, only a minority (20%) of participants had ever attended a pulmonary rehabilitation program. Possible explanations for this under utilization include a lack of awareness of the benefits, the need for physician referral for attendance, and a lack of access to pulmonary rehabilitation programs.²⁰ This study revealed that the use of exercises (breathing, strengthening, and aerobic) is suboptimal and that this was related to a lack of knowledge of their existence and how to perform them. An implication for clinicians is to translate the evidence related to exercise, teach them how to perform the strategies, and encourage their use.

A survey design was used and thus received data that relied on patient recall. However, the study achieved a relatively high response rate (78%), which decreases the possibility of respondent bias. Based on a review of addresses and postal codes, there was representation of the various Ontario regions. As a result, our study has greater representation of patients with COPD than a study performed in a few urban teaching centers because participants were from across the province and from a variety of practice settings and care providers. Unfortunately, because our study was community based and not dependent on physicians as a means to participate, the investigators do not have information regarding lung function tests or

measures of exercise capacity, which would assist with confirmation of COPD and identifying severity. An MRC Dyspnea scale may have assisted with disability stratification but was not assessed. However, all participants reported having physician confirmed COPD, daily respiratory symptoms, exposure to cigarette smoke, and daily bronchodilator use.

In conclusion, the results of the survey reveal that individuals with COPD are using a variety of strategies to manage their illness including the use of inhaled bronchodilators (short and long acting) and corticosteroids, annual influenza vaccinations, breathing exercises, aerobic exercise, and regular visits with their physician. Common motivators for using these strategies are fear of getting worse, an improved sense of well being, and that their health care provider recommended it. The most common barriers to use are not knowing about the strategy, interruptions in daily routine (appointments, visitors, travel), and mood. A significant proportion of participants are at risk of depression, which can affect their self-care. Our study suggests that clinicians can assist patients with COPD to become self-managers by translating the recommendations of the COPD guidelines, encouraging the use of the various strategies, being alert to depression, and ensuring that patients have the knowledge and skills to perform the strategies. Participants identified health care professionals as the preferred method of learning and as an important motivator for performing self care activities. Encounters with patients with COPD present an important opportunity for clinicians to assist them with their constant struggle to manage and live with the condition.

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