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ORIGINAL RESEARCH

Perceptions and Attitudes Toward the Use of Nebulized Therapy for COPD: Patient and Caregiver Perspectives

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Abstract

Although delivery of medications through nebulization is effective for patients with COPD, nebulization is often perceived negatively. This survey evaluated patient and caregiver attitudes and perceptions related to the use of nebulization for the management of COPD. A total of 400 patients and a separate population of 400 caregivers were randomly selected and interviewed via telephone. Responses were assessed on the basis of 4 domains: health of patients with COPD, satisfaction with nebulization therapy, benefits and challenges, and the caregiver role. Most patients (58%) self-classified their COPD as "mild to moderate," with shortness of breath upon minimal to moderate exertion; caregivers reported similar findings. The majority of patients and caregivers (89% and 92%, respectively) were "generally satisfied with their (or their friend's or family member's) current nebulized treatment." Based on their personal experiences, 80% of patients and caregivers reported that using a nebulizer was better than using only an inhaler. Patients and caregivers agreed (79% and 85%, respectively) that the benefits of nebulization therapy outweighed the difficulties or inconveniences. Patients believed that their overall quality of life had improved since beginning nebulization (75%) and that nebulization better enabled their caregiver to provide care (77%); caregivers echoed this sentiment. Overall, this survey demonstrated that an overwhelming majority of patients and caregivers were satisfied with nebulization therapy, reporting benefits in symptom relief, ease of use, and improved quality of life.

Introduction

Inhaled medications are a cornerstone of treatment for patients with chronic obstructive pulmonary disease (COPD) (1). They offer a targeted mode of drug delivery that produces higher local concentrations and less systemic exposure, which potentially leads to improved efficacy as well as better safety compared with systemic modes of delivery (2). A variety of delivery systems are available for inhalation therapy in patients with COPD, including pressurized metered-dose inhalers (pMDIs), dry powder inhalers (DPIs), and nebulizers (1,2), each of which is associated with its own advantages and limitations (1–3). To begin, pMDIs are portable and can deliver effective doses of a medication to the airways. In addition, formulating or combining medications is easily achievable with this device. Using a pMDI, however, requires repeated training due to the multiple steps needed for adequate drug delivery. The use of spacers may help ease this technique-related burden.

Although DPIs are newer and easier to use than pMDIs, DPIs rely on a minimum inspiratory flow to achieve adequate drug delivery that may be

† Died October 26, 2011.

Keywords: nebulization, survey, inhaler device, device selection

Correspondence to: Amir Sharafkhaneh, Associate Professor of Medicine, Baylor College of Medicine, MEDVA Medical Center Bldg. 100 (111i), Houston, TX 77030, USA, phone: 713-794-7668, fax: 713-794-7295, email: amirs@bcm.tmc.edu difficult to achieve by some patients with COPD who have severe airflow limitation and/or inspiratory muscle weakness (2,5,6). In contrast to both pMDIs and DPIs, nebulized therapy does not require a special technique nebulizers deliver the drug over many breaths and thus do not require steps to actuate the device, nor do they require a minimal inspiratory flow rate to appropriately deliver the medication to the lungs. However, nebulization is associated with a relatively long administration time, and there are steps involved in cleaning and maintaining the device. In general, when used correctly, these 3 forms of inhalation devices are equally effective in delivering medication to the lungs (2,5,6). As such, these differences among the inhalational devices may contribute to varying patient attitudes and beliefs regarding their use.

Selection of the optimal inhaled medication delivery device for the management of COPD should consider the patient's needs, capabilities, preferences, and the device's impact on the patient's overall health status. In some patients, the information needed to make recommendations may come from the caregiver (4,5). For many patients with COPD, caregivers play a major role in the day-to-day management of their disease and influence their clinical decision making. Patient and caregiver attitudes toward inhaled therapy and device preferences depend on a number of factors, including convenience, ease of use, and perceived efficacy (4). In practice, perceived efficacy of therapy is likely to have a strong influence on adherence to inhaler therapy and, therefore, long-term clinical outcomes (4,7).

Although nebulization offers an effective mode of drug delivery (5), data regarding patient and caregiver perspectives about this therapy are lacking (7). Therefore, this survey sought to evaluate 4 key domains of patient and caregiver perceptions and attitudes relating to the use of nebulization for the management of COPD: health of the patient with COPD, satisfaction with nebulization therapy, benefits and challenges, and the caregiver role. We surveyed self-reported assessments of the health and related behaviors of patients with COPD, identified the principal benefits and challenges associated with nebulization therapy, and explored the caregiver role in patients' nebulization therapy.

Methods

Survey Population

Patients currently receiving nebulized therapy as well as caregivers (who were caring for a different set of patients) were randomly selected from a national commercially available sample of self-reported COPD households compiled from a variety of sources (i.e., direct outreach, magazine, and publication subscriptions). This database is a leading self-reported database containing accurate information pertaining to consumers' ailments and usage of prescription and over-the-counter pharmaceuticals. The information has been collected through sur-

veys given directly to consumers. Patients were included in the survey and subsequently interviewed if they met all of the following criteria: adults ≥18 years of age; selfreported COPD, chronic bronchitis, and/or emphysema, as diagnosed by their physician; and currently receiving nebulization treatment for their breathing condition. Patients who did not meet these criteria were excluded from the survey; there were no additional exclusion criteria. The survey predetermined that a sample size of 400 patients and 400 caregivers would provide sufficient data to determine their perceptions and attitudes towards nebulized therapy. Thus, responses from patients and caregivers who were interviewed beyond the 800 required participants were subsequently not included in the survey, even though they met all inclusion criteria.

For the purposes of this survey, "self-reported" meant that patients themselves conveyed their diagnosis of COPD to the interviewer after being asked: "Have you been diagnosed by a physician as suffering from any of the following" among which COPD was a choice. The survey did not confirm the diagnoses objectively or by review of patients' medical records. Disease severity was assessed subjectively. Throughout the survey, unless noted otherwise, disease severity was self-reported by patients; in the case of caregivers, severity was reported for the patients they were caring for. Disease severity was also assessed based on predefined criteria regarding day-to-day limitations. Criteria for "very severe" COPD included "too breathless to leave the house," "breathless when dressing and/or undressing," and "use of oxygen to aid in breathing." The inclusion and exclusion criteria for caregivers of patients with COPD were identical to those for patients; however, in the caregiver's case, they were responding on behalf of the person they cared for. The caregiver population did not overlap with the patient population (i.e., caregivers included in this survey did not care for the patients who were surveyed).

Design/Procedures

Mylan Specialty L.P. and the COPD Foundation designed and executed the survey. The COPD Foundation is an organization of health care professionals, researchers, volunteers and patient advocates who work together to expand the education, research, and public policy efforts to increase awareness of and action related to COPD. These programs align to support the organization's mission of improving the quality of life for those living with and affected by COPD (www.copdfoundation.org). The design and execution of the survey was done in collaboration with KRC Research, a firm specializing in health care communications and consumer research, and with Discovery Research Group (DRG), a market research company specializing in survey data collection.

Mylan Specialty L.P. internally developed key domains and survey questions (see Supplemental tables) to evaluate the benefits and challenges of nebulization among patients and caregivers. The following key domains were



established: health of patients with COPD (evaluated patients' perceptions of their overall health and, specifically, their COPD), satisfaction with nebulization therapy (evaluated patients' overall experience with nebulization and degree of satisfaction with this mode of delivery), benefits and challenges (evaluated patients' perceptions on the positive and negative aspects of nebulization and its impact on overall quality of life), and the caregiver role (evaluated the extent of the caregiver's involvement in the care of their friend/loved one with COPD, in addition to the caregiver's experiences with nebulization on their friend/loved ones' behalf). KRC Research then collaborated with Mylan Specialty L.P. on the survey design, including the development of questions associated with each domain that would best capture and meet the intended objectives. The COPD Foundation reviewed and validated the final survey design and questions with its medical advisory team.

To execute the survey, DRG conducted 12-minute, random-digit-dial telephone interviews with patients and caregivers from January 26, 2009 through February 10, 2009. There were 67 interviewers involved, all of whom had prior experience in conducting health care—targeted interviews. The interviewers underwent a comprehensive, 4-day, 16-hour initial training program, during which they were trained on policies and procedures specific to DRG's standards and guidelines for maintaining high quality in the market research industry. Finally, KRC Research tabulated the results from the telephone interviews and provided a comprehensive analysis of the findings to Mylan Specialty L.P.

Statistical Analysis

Statistical analyses were primarily descriptive in nature, as comparisons were made between participant responses stratified by age and severity of COPD. Crosstabulation was applied to dissect the data by major demographic points. Further, a formal power analysis was not conducted. Instead, the chosen sample size reflected what was deemed necessary to perform basic segmentation and achieve the key objectives of the survey. The data were weighted to reflect the demographic and geographic distribution of patients with COPD in the United States (guided by the Centers for Disease Control and Prevention 2006 National Health Interview Survey). The statistical significance was tested at a 95% confidence level, and the estimated margin of error at this confidence level for each sample (n = 400) for proportions near 50% was set at \pm 5.0%.

Results

A total of 400 patients with COPD and a separate population of 400 caregivers for a friend or family member with COPD were randomly selected and interviewed via telephone (Figure 1). The participants were predominately females (65%) aged 65 years or older (50%). In both the "Patient" and "Caregiver" cohorts, 8% of patients with COPD were 18–44 years of age (1% of patients were in the ranges of 18–24 years and 25–34 years, each; 6% of patients were 35–44 years of age) (Table 1). Patients were most commonly being managed by a specialist (54%), and most caregivers (55%) identified themselves as the

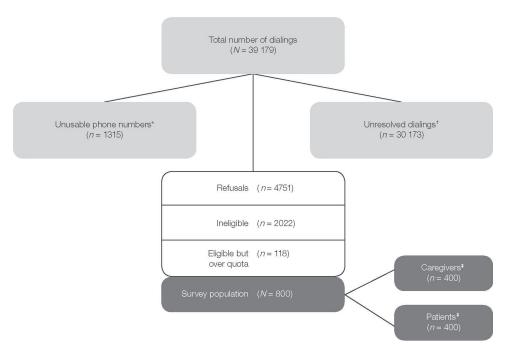


Figure 1. Sample Selection*: Disconnected, fax number, business phone, language barrier, wrong number; †: No answer, busy signal, answering machine, respondent not available; ‡: Patients were included in the survey and subsequently interviewed if they met all of the following criteria: adults ≥ 18 years of age; self-reported COPD, chronic bronchitis, and/or emphysema (each condition had to be physician-diagnosed); and currently receiving nebulization treatment for their breathing condition. Patients who did not meet these criteria were excluded from the survey; there were no additional exclusion criteria. The inclusion and exclusion criteria for caregivers of patients with COPD were identical to those for patients; however, in the caregiver's case, they were responding on behalf of the person for whom they cared.



Characteristics	Patients (<i>n</i> = 400) <i>n</i> (%)	Caregivers $(n = 400)$ n (%)	
Gender			
Male	140 (35)	149 (37)	
Female	260 (65)	251 (63)	
Age, y			
18–44	32 (8)	32 (8)	
18–24	4 (1)	5 (1)	
25–34	5 (1)	5 (1)	
35–44	23 (6)	22 (5)	
45–64	168 (42)	157 (39)	
≥65	200 (50)	211 (53)	
Asthma diagnosis	5 (1)	5 (1)	
Time on nebulized therapy			
<6 years	211 (53)	271 (68)	
Use of nebulized therapy			
Both rescue and maintenance	179 (45)	210 (53)	
Solely for maintenance	134 (33)	114 (29)	
Solely for rescue	72 (18)	53 (13)	

spouse of the patient they were caring for with COPD. More than one-third of caregivers (38%) reported spending \geq 16 hours per week caring for their friend or family member.

Health of the Patient With COPD

Nearly all (99%) of the patients reported having a physician-diagnosed smoking-related lung disease, including COPD, chronic bronchitis, or emphysema. The majority of patients (77%) were diagnosed with COPD \geq 6 years prior to the survey, and all patients were receiving nebulized therapy (Table 1). The majority of patients were receiving other forms of inhaled therapy in addition to nebulization, including MDIs (59%), DPIs (57%), and oxygen (34%) (Table 2).

As shown in Figure 2, more than 40% of patients reported shortness of breath upon minimal to moderate exertion, with over 50% of caregivers reporting similar results on behalf of their friend or family member. When specifically asked about the activity level that results in shortness of breath, only 36% of patients (n =145) reported that they "experience breathlessness with strenuous exercise." In contrast, the rest of the patients reported experiencing breathlessness when walking on a flat surface at their own pace (62%; n = 249) and when walking up a slight hill (66%; n = 265). Further, 42% of patients (n = 168) reported breathlessness while dressing and/or undressing, and 19% of patients (n = 75) reported that they were too breathless to leave the house. The caregivers reported similar percentages in response to the same questions.

Therapy	Patients (<i>n</i> = 400) <i>n</i> (%)	Caregivers $(n = 400)$ n (%)
MDI		
Albuterol	178 (44)	190 (47)
Ipratropium bromide	66 (17)	71 (18)
Ipratropium bromide/albuterol sulfate	64 (16)	70 (18)
DPI		
Fluticasone propionate/ salmeterol	165 (41)	157 (39)
Tiotropium bromide	112 (28)	131 (30)
Formoterol fumarate	20 (5)	21 (8)
Salmeterol xinafoate	17 (4)	32 (5)
Oxygen	137 (34)	195 (49)
Budesonide/formoterol fumarate DPI	3 (1)	2 (1)
Other	13 (3)	8 (2)
Don't know/refused		

Satisfaction With Nebulization Therapy

The majority of patients and caregivers (89% and 92%, respectively) were "satisfied" with their current nebulized treatment. This net satisfaction for patients translated across different age groups, with 100%, 89%, and 88% of patients aged 18-44 years, 45-64 years, and ≥ 65 years, respectively, reporting satisfaction with nebulized treatment. Patients who were most likely to be "extremely satisfied" or "very satisfied" (89%) included those who reported not having severe COPD (67%), those who claimed to receive a sufficient amount of information regarding COPD from their physicians (66%), those who did not use inhalers in addition to their nebulizers (65%), those who were female (63%), and those who used nebulization therapy for long-term use (61%). Caregivers who were most likely to be "extremely satisfied" or "very satisfied" with their patient's current nebulized treatment (61%) included those whose patients were using nebulization therapy for "quick relief" purposes (70%), those who agreed that using a nebulizer was better than using an inhaler alone (66%), those who reported playing a "significant" role in their patient's therapy (65%), and those who lived with the person they were caring for (60%).

Patients less likely to be satisfied with their current nebulized treatment (7%) included those who agreed that using a nebulizer was "no different" from using an inhaler (22%), those who claimed to receive little information regarding COPD from their physicians (16%), those who had been diagnosed with COPD < 6 years ago (11%), those who did not have a live-in caregiver (11%), and those who reported having "severe" COPD (11%). Caregivers less likely to be satisfied with their friend's or family member's current nebulized treatment

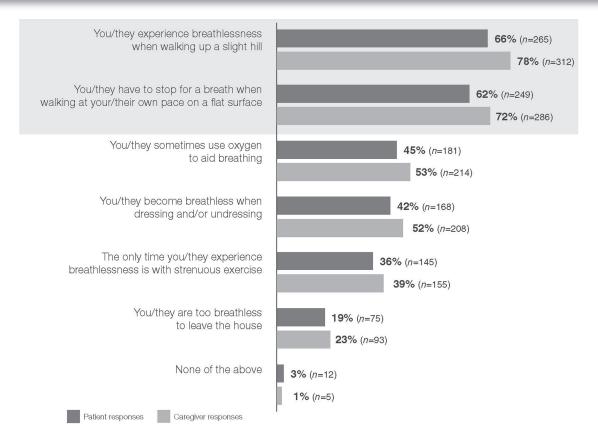


Figure 2. Assessment of COPD. Patient question: Which of the following statements accurately describes your current condition? Caregiver question: Which of the following statements accurately describes this patient's current condition? Percentages are based on rounding and reflect only patients who responded to the given question. COPD: chronic obstructive pulmonary disease.

(6%) included those who agreed that using a nebulizer was "no different" from using an inhaler (13%), those who received little information about COPD from their patient's physicians (12%), and those who did not live with the person they were caring for (9%).

Based on their experiences, 80% of both patients and caregivers reported that using a nebulizer was better than using only an inhaler, with 12% of patients citing no difference in this regard.

Benefits and Challenges

Without being prompted, 68% of patients and 65% of caregivers reported easier breathing as the most positive aspect of nebulization therapy. When prompted, the vast majority of patients and caregivers cited benefits of nebulization as the ability to "breathe easier" (91% and 95%, respectively) and "chest felt more comfortable" (86% for both) (Figure 2). As shown in Figure 3, many caregivers (88%) also reported that their friend or family member had "more control of his or her symptoms" as a result of nebulizer use.

Younger patients (18–44 years of age) were more likely than older patients (\geq 65 years of age) to agree with the physical benefits of nebulization therapy, i.e., "you can breathe easier" (100% and 89%, respectively; p < 0.05) and "your chest feels more comfortable" (100% and 83%, respectively; p < 0.05). Significantly more patients aged 45–64 years (vs. patients aged 18–44 years and \geq 65 years) reported "having more control of

symptoms" (89%; p < 0.05) and that they were "able to be more physically active in daily life" (80%; p < 0.05). In addition, significantly more patients with "less severe" (vs. "severe") COPD agreed with the positive aspects of nebulization, particularly "your chest feels more comfortable" (90% and 81%, respectively; p < 0.05), "you have more control of your symptoms" (90% and 77%, respectively; p < 0.05), "you are more confident that you are getting the right amount of medicine with each dose" (89% and 78%, respectively; p < 0.05), "you are able to be more physically active in your daily life" (82% and 63%, respectively; p < 0.05), and "you are able to make fewer unscheduled visits to your doctor or hospital" (78% and 64%, respectively; p < 0.05).

Unprompted, 25% of patients (p < 0.05) and 17% of caregivers cited the immobility or bulkiness of the device as a primary disadvantage of nebulization therapy, with the "time-consuming" component (12% for both) and "side effects" (12% and 10%, respectively) associated with therapy as additional disadvantages (Table 3). The majority of patients and caregivers (79% and 85%, respectively) agreed that the benefits of nebulization therapy outweighed the difficulties or inconveniences, and that overall quality of life had improved with nebulization (75% and 82%, respectively). In addition, 77% of patients reported that nebulization therapy had made it easier for their friend, family member, or caregiver to help care for them, while 85% of caregivers reported that it had made it easier to provide care (Figure 4). Specific

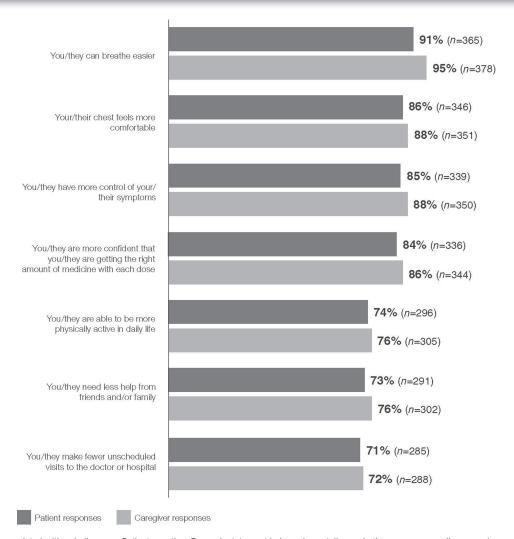


Figure 3. Benefits associated with nebulizer use. Patient question: For each statement below, please tell me whether you agree or disagree, given your own experiences with a breathing disorder. As a result of using a nebulizer... Caregiver question: For each statement below, please tell me whether you agree or disagree, given your own experience as a caregiver. As a result of using a nebulizer... Percentages are based on rounding and reflect only patients who responded to the given statement.

Table 3. Primary disadvantages of nebulization therapy

QUESTION. What do you see as the main negatives or disadvantages of nebulization?^a

	Patients (n = 400) n (%)	Caregivers (<i>n</i> = 400) <i>n</i> (%)
No negatives	86 (21)	110 (27)
Device is immobile/bulky/ cumbersome to transport	102 (25)	68 (17)
Time-consuming	48 (12)	47 (12)
Side effects ^b	46 (12)	38 (10)
Inconvenient/Don't like doing it	25 (6)	32 (8)
Have to use it several times a day	10 (3)	12 (3)
Care and cleanup after use	8 (2)	13 (3)
Too expensive	6 (2)	8 (2)

*Percentages are based on rounding and reflect only patients and caregivers who responded to the given question. *The side effects that were provided as unprompted responses for patients and caregivers, respectively, included: Shakiness (5% and 2%); cough/sore throat (2% and 1%); nervousness (1% and 2%); dry or foul mouth (1% each); rapid heartbeat (1% each); dizziness (1% each); other (2% each). The "other" was not specified for either cohort.

to the patient cohort, such benefits were significantly more prominent in younger patients aged 18-44 years as compared with their older counterparts (87% and 100%, respectively; p < 0.05). Lastly, patients and caregivers (56% and 65%, respectively) wished nebulization therapy would have been initiated sooner (Figure 4).

The Caregiver Role

The majority of caregivers (54%) reported playing a "significant" (moderate to major) role in the overall care of their friend or family member, particularly with regard to their nebulization therapy. This role included, but was not limited to, the assembly of the nebulizer and air compressor, administering the treatment, and the care and cleanup of the nebulizer afterward.

Discussion

We report the results of a survey evaluating the attitudes and perceptions of self-reported patients with COPD and caregivers of patients with COPD who use nebulization therapy. The overwhelming majority of patients and



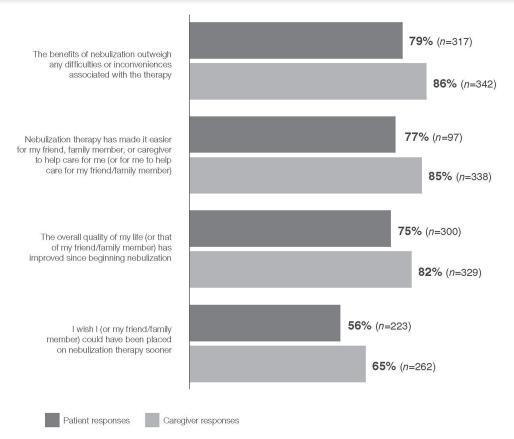


Figure 4. General perceptions of nebulization. Patient/Caregiver question: For each statement below, please tell me whether you agree or disagree. Percentages are based on rounding and reflect only patients who responded to the given statement.

caregivers were satisfied with nebulized therapy, with 80% reporting that use of a nebulizer was better than use of an inhaler alone. Participants identified easier breathing as the major reason for their satisfaction with nebulized therapy, while the immobility and bulkiness of the device, the administration time, and the side effects associated with the therapy were recognized as key disadvantages. Our study is unique because it is the largest survey conducted among patients with COPD who use nebulization, and it is the first of its kind to explore the perspectives of caregivers on the role of respiratory devices, particularly nebulizers.

Few studies have evaluated patient perspectives toward inhalational devices, particularly nebulization (8,9). Barta and colleagues surveyed 82 patients using home nebulizer treatment on 4 key domains, including personal well-being, symptom control, increased confidence, and perception of greater independence. Participants reported satisfaction in all 4 domains with the use of nebulized therapy (8). The current study confirms and expands findings from prior studies in a much larger sample of patients with COPD who use nebulization.

Use of multiple devices in patients with COPD is perceived as a possible burden. The current survey demonstrates that the majority of patients use multiple delivery methods because of worsening symptoms. This finding is consistent with key COPD guidelines recommending step-up therapy for patients with worsening

disease (1,10). Interestingly, patients and caregivers positively viewed the addition of nebulization to their other medications. This indicates a willingness of caregivers and patients with COPD to accept the use of multiple devices when they perceive a clear benefit.

An interesting finding of our study is the effect of disease and treatment-specific patient education on patient satisfaction with therapy. Our data indicate that the patient and caregiver education provided by physicians produced a positive attitude in both; hence, patient disease-related education was among the factors contributing to satisfaction with nebulization. In contrast, the participants who received less disease-specific education were less likely to be satisfied with nebulization. Similarly, lack of disease and treatment-specific education to caregivers negatively impacted their satisfaction with nebulization.

Our study expands the findings to the caregivers of patients receiving nebulized therapy. The caregivers in our study reported a similar degree of satisfaction with nebulized therapy in the various domains. Our study also shows that caregivers who are more involved in the day-to-day care of patients reported a higher satisfaction with nebulization therapy, perhaps because nebulization allows more involvement and participation on behalf of the caregiver. It may also be an indirect indication of caregivers' perceived efficacy of nebulization, in that caregivers noticed an improvement in patients' acute and/or chronic symptoms as a result of nebulization.

Disadvantages of nebulizers include bulkiness and lack of portability and the relatively long administration time needed to deliver medications (5,6). Our study does not demonstrate major concerns/negative perceptions associated with such disadvantages, however. The patients and caregivers overwhelmingly agreed that the many advantages of nebulized therapy exceeded the disadvantages.

Our study has important limitations, primarily due to the patient population studied and the survey design. A large number of individuals were approached to obtain a final sample of 400 participants in each of the patient and caregiver categories. The survey design does not allow for attribution of findings to benefits of nebulizer device (e.g., findings may also be influenced by severity of disease, duration of COPD, the nebulized medication used, and the synergistic effects of other medications). The survey design does not provide the capacity to conduct a clinical evaluation comparable to a patient's self-identification of his or her condition and the severity of that condition. The survey also did not allow for an objective measurement of pulmonary function to support the diagnosis of COPD. A higher-order statistical analysis, which would be necessary to provide a direct correlation between nebulization therapy and improved patient health, was not conducted. Patient and caregiver findings are independent of one another, making it difficult to draw conclusions about the impact of patientcaregiver relationships on patient preference or COPD management. The overall findings are subjective, potentially limiting their clinical applicability.

Conclusions

The current survey confirms and expands the findings of other studies of patients' perceptions about the use of nebulization. The survey demonstrates that an overwhelming majority of patients reported satisfaction with nebulization. The survey is unique in that it explored the caregiver perspective of nebulization, the majority of whom expressed satisfaction with its use. Both patients and caregivers reported improvements in symptomatic control and overall quality of life with the use of nebulization to manage COPD.

Declaration of Interest Statement

Dr. Sharafkhaneh has served on advisory boards of Mylan Specialty L.P. and GlaxoSmithKline. He has also participated in Speaker Bureau activities for Glaxo-SmithKline, Pfizer, and Boehringer Ingelheim. Dr. Wolf

is an employee of Mylan Specialty L.P. Dr. Hanania has received research grant support and served as a consultant for Mylan Specialty L.P. Dr. Make has served on the advisory boards of Mylan Specialty L.P. and Sunovion. His work is supported by the Office of Research & Development, Michael E. DeBakey Veterans Affairs Medical Center. Dr. Tashkin has served on the advisory boards of Mylan Specialty L.P. and Sunovion and as a speaker for Mylan Specialty L.P. He has also received grant support from Mylan Specialty L.P. and Sunovion.

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490

Don't know/refused



Continues

Supplemental Table: Continued				
Question	Answer choices			
What is the primary purpose of the nebulized treatment you are currently using?	 To administer rescue or "quick relief" medications To administer preventive or long-term medications For both rescue and long-term use Don't know/refused 			
On an average day, how many times per day do you take your nebulized treatment?	 Less than 1 time per day Once a day Twice a day 3 times a day 4 times a day 5 times a day or more Don't know/refused 			
Do you have someone that helps care for you on a regular basis? This includes helping you administer any breathing disorder- related treatments	 Yes No Don't know/refused 			
Thinking of the person who helps you with your breathing disorder, what is their relationship to you?	 Spouse Home health care nurse Child Sibling Parent Friend Other relative Don't know/refused 			
Does this person currently live with you?	 Yes No Don't know/refused 			
How long have you been using a nebulizer?	 Less than 1 year ago Between 1 and 2 years ago Between 3 and 5 years ago Between 6 and 10 years ago More than 10 years ago Don't know/refused 			
Generally, how satisfied are you with your current nebulized treatment?	 Extremely satisfied Very satisfied Somewhat satisfied Not very satisfied Not at all satisfied Don't know/refused 			
In your view, what are the most positive aspects of nebulization? (open-ended question)	• N/A			
What are the main negatives or disadvantages of nebulization? (open-ended question)	• N/A			
Are you currently using an inhaler in addition to your nebulizer?	 Yes No Don't know/refused 			
As a result of using a nebulizer, would you say you strongly agree with this statement, somewhat agree, somewhat disagree or do you strongly disagree?	 You can breathe easier Your chest feels more comfortable You have more control of your symptoms. You are more confident that you are getting the right amount of medicine with each dose You are able to be more physically active in your daily life You need less help from friends and/or family You make fewer unscheduled visits to your doctor or the hospital 			
Based on your own experience, would you say that using a nebulizer is better, worse, or no different than using only an inhaler?	 Better Worse No different Don't know/refused 			
Would you say you strongly agree with this statement, somewhat agree, somewhat disagree or do you strongly disagree?	 The benefits of nebulization outweigh any difficulties or inconveniences associated with the therapy Nebulization therapy has made it easier for my friend, family member, or caregiver to help care for me The overall quality of my life has improved since beginning nebulization I wish I could have been placed on nebulization therapy sooner than I was 			
What type of physician do you see to manage your breathing disorder?	 Pulmonologist, or doctor who specializes in lungs and breathing Primary care provider or general practitioner Allergist Other Don't know/refused 			



Supplemental Table. Caregiver Questions^a

Question Answer choices

Do you have a close friend or relative who has been diagnosed with a breathing disorder that you help on a regular basis? This includes help administering any breathing disorder-related treatments. It could be someone who just needs a little help, someone in declining health, or someone who is seriously or chronically ill.

Do you currently live with the person you help care for?

In your best estimate, how many hours per week, on average, do you dedicate to the care of this person's breathing disorder?

How much of a role do you personally play in this person's nebulization therapy? This can include, but is not limited to, the assembly of the nebulizer and air compressor, the administering of the treatment, as well as the care and cleanup thereafter

Which of the following statements accurately describes this person's current condition?

NOTE: The classifications in bold were provided to KRC before the research was conducted in order to determine significant differences, if any, between self-reported perception of severity and suggested guidelines for each classification description.

- Yes
- No
- Don't know/refused
- Yes
- No
- Don't know/refused
- Less than 5 hours per week
- Between 5 and 10 hours per week
- Between 11 and 15 hours per week
- Between 16 and 20 hours per week
- More than 20 hours per week
- Don't know/refused
- Major role
- Minor role
- Moderate role
- No role at all
- Don't know/refused

MILE

The only time they experience breathlessness is with strenuous exercise

MODERATE

They experience breathlessness when walking up a slight hill

SEVERE

They have to stop for a breath when walking at their own pace on a flat surface

VERY SEVERE

They sometimes use oxygen to aid their breathing They become breathless when dressing and/or undressing

They are too breathless to leave the house

- None of the above
- Don't know/refused



^{*}These questions were unique to the caregiver cohort. Beyond these questions, caregivers were asked the same questions as those listed in "Supplemental Table: Patient Questions."