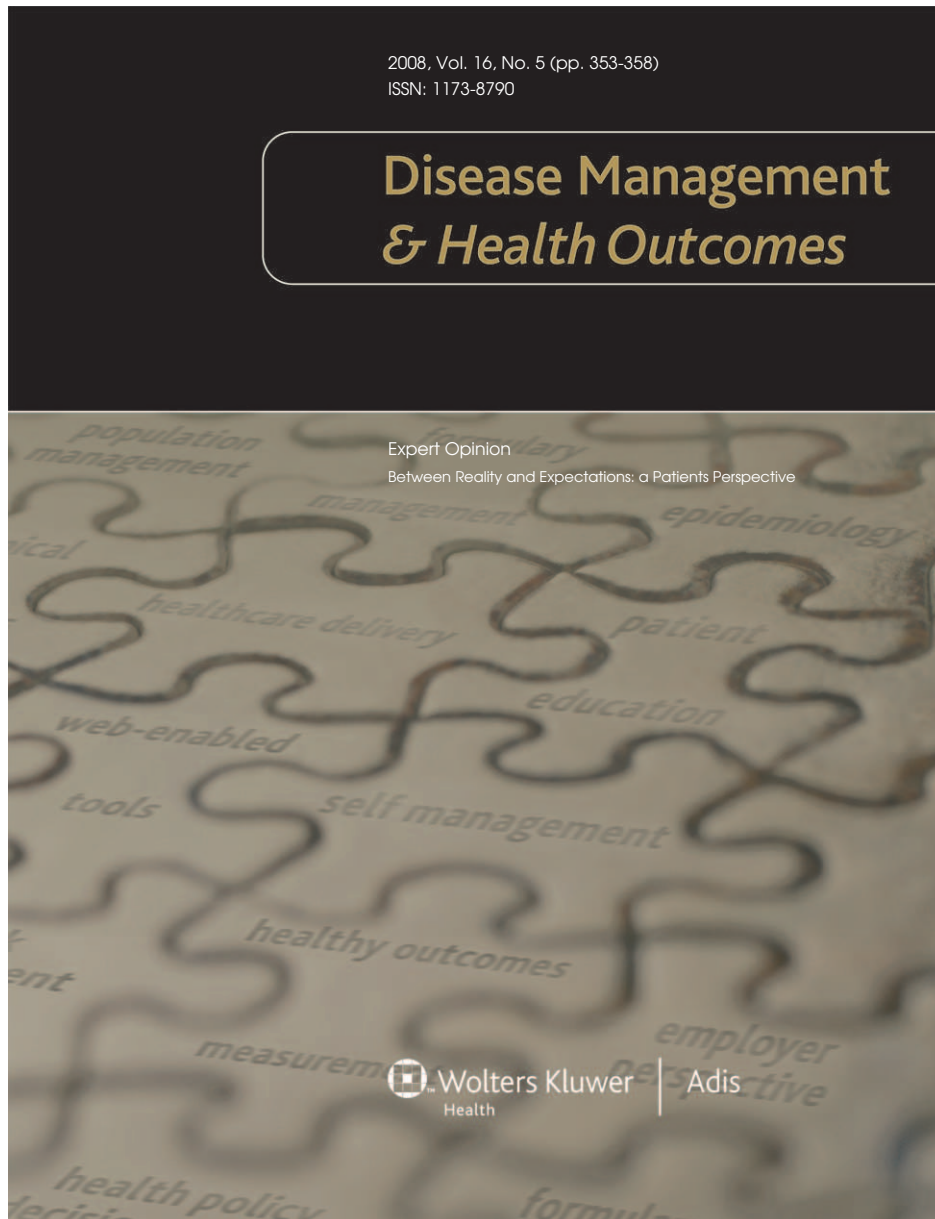


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Patients with Chronic Obstructive Pulmonary Disease

Between Reality and Expectations – A Patient's Perspective

Włodzimierz 'Vlady' Rozenbaum

COPD-ALERT, International Online Patient Support & Advocacy Group, Silver Spring, Maryland, USA

Abstract

For many years, chronic obstructive pulmonary disease (COPD) has been under-recognized and stigmatized. Misconceptions about this disease have led to under-treatment and under-funding, resulting in an increase in the burden of COPD.

In 2005, the National Emphysema/COPD Association published the results of a set of national surveys of patients, primary care physicians, and pulmonologists. The findings of these surveys indicated that activity limitation was prevalent among patients with COPD, and that, although most physicians believed that effective therapy could slow the progression of COPD, their inadequate knowledge and poor adherence to practice guidelines had a negative impact on the care of patients with COPD.

Patients with COPD may not be optimally treated by physicians. Greater attention needs to be paid to effective smoking cessation programs and self-management. Many physicians under-prescribe effective therapies, with some patients experiencing the ill effects of long-term systemic corticosteroids.

Ambulatory oxygen is an effective therapy for COPD. However, the use of ambulatory oxygen can make daily living and leisure activities difficult for patients, and thus physicians have difficulty convincing patients to initiate this therapy. Attention needs to be paid to finding the right oxygen delivery system for the patient, and to educating patients on the correct use of this therapy, particularly when travelling. Another important issue surrounding oxygen therapy is sleep anxiety and the fear of breathlessness or dying in one's sleep.

COPD exacerbations have a major impact on quality of life; however, most therapies used to treat exacerbations have been designed for the treatment of asthma. Corticosteroids, antibacterials, and bronchodilators are routinely used for the treatment of exacerbations, but physicians often do not follow practice guidelines. Exacerbation management is too often 'too little, too late.' Another area of concern for patients is effective use of inhalers; incorrect inhaler technique is too common.

It has been established that pulmonary rehabilitation programs should be an integral part of the management of COPD, particularly in patients with moderate or severe disease. Currently, the availability of pulmonary rehabilitation programs in the US is limited, as reimbursement is either inadequate or not available. In addition, many physicians do not refer patients to these programs when they are available.

Medical advances notwithstanding, most patients with COPD demand therapies that are more effective, more enabling, and cause fewer adverse effects than current therapies. The challenge for medical science and the pharmaceutical industry is to bring about a qualitative change in therapy for the acute exacerbations of COPD as well as for the perpetual shortness of breath, which has such a devastating effect on quality of life. It is very encouraging that the medical community is beginning to recognize this challenge and is moving towards treating patients with COPD as 'whole people' and training them to self-manage at home. The overall success of these efforts is dependent on the recognition of COPD as a national health priority.

In January 2007, the National Heart Lung and Blood Institute (NHLBI) launched a national chronic obstructive pulmonary disease (COPD) awareness and education campaign: 'Learn More Breathe Better'.^[1] This campaign is "finally moving [COPD] from obscurity to prominence"^[2] with the purpose of sending the message that COPD, although serious, is treatable, but also "to narrow the gap between what is commonly being done for COPD patients today and what can, in fact, be done."^[2] This is a very tall order, indeed, as it must satisfy the urgent need of physicians and patients for complete and credible information.

For many years, COPD has been what Mrs Grace Anne Dorney Koppel – the patient spokesperson for the NHLBI awareness campaign and the wife of a prominent newscaster, Ted Koppel – calls fittingly "the Rodney Dangerfield of diseases." It gets no respect. Others say that the 'O' in COPD stands for 'obscure' or 'overlooked.'^[3] These sentiments are rooted in prejudice against the disease, which is considered by many inside and outside the medical profession as self-inflicted and shameful. However, more importantly, these sentiments reflect insufficient knowledge by physicians about the disease, its diagnosis, and available treatment. Coupled with lack of awareness of COPD by the population at large, and highly disproportionate allocation of funds for COPD research by the National Institutes of Health,^[4] these factors have a devastating effect on millions of patients, who expect prompt recognition of their acute health problems and hope for effective treatment. These misconceptions also precipitate rapid escalation of healthcare costs: \$US42 billion a year already. COPD is also the second leading cause of disability.^[3,5]

The Global Initiative for Chronic Obstructive Lung Disease (GOLD) offers comprehensive standards for the diagnosis and treatment of COPD to the international community.^[6] These standards focus on four components of COPD management: (i) assessment and monitoring of the disease; (ii) reducing risk factors; (iii) managing stable COPD by applying education, and pharmacological and non-pharmacological treatments; and (iv) managing exacerbations in home and hospital settings. The implementation of the GOLD standards places increased demands on physicians and, very importantly, requires that patients are given the necessary tools to effectively manage their disease in order to improve their quality of life and the medical care they receive. This is a formidable challenge, considering the limited amount of time allotted for patient visits and the limited availability of pulmonary rehabilitation programs nationwide, both of which are compounded by reimbursement problems.

1. The National Emphysema/Chronic Obstructive Pulmonary Disease Association Surveys

Four years ago, the National Emphysema/COPD Association (NECA), a patient organization, commissioned a set of national surveys of patients, primary care physicians, and pulmonologists "to evaluate patient and physician perceptions of severity and quality of life, attitudes about COPD and its causes, health insurance barriers to COPD-related care, sources of information and knowledge, and the current practice of diagnosis and treatment of COPD." The surveys led to the following conclusions: "Patients with COPD have a high prevalence of activity limitations. Although most physicians believed that proper treatment can slow progression, inadequate knowledge and poor adherence to practice guidelines, together with insurance impediments, negatively impact COPD care."^[7]

Specifically, the patient survey revealed the following important issues.

1. Dyspnea: almost without exception a universal symptom of COPD that occurs on a daily basis, often severely limiting the ability to work.
2. Perception of health status: 37% rated their health status as poor or very poor, 5% as excellent.
3. Perception of healthcare: 85% were somewhat or very satisfied, and 14% somewhat or very dissatisfied; among those patients who described their health as poor or very poor, 85% were somewhat or very satisfied (indicating that patients who felt they had poor health status did not have a low opinion of the healthcare they received).
4. Health insurance: 12% declared no coverage, 70% reported that insurance coverage had not negatively affected their therapy.
5. Sources of information about COPD: 77% obtained information from physicians; 47% from the internet; 38% from nurses; 22% from respiratory therapists; 13% from television; and 3% from patient organizations. Notably, only 25% felt they were well informed about COPD and its treatment, while 36% thought they were poorly or less than adequately informed.
6. Disease management and treatment: 50% of patients were under the care of a general practitioner; 12% were treated by a general internist; and 30% by a pulmonologist. Some 8% reported not having received any lung function tests and only 4% recalled being tested for alpha-1 antitrypsin deficiency. Some 80% reported regular use of inhalers (types were not specified), while 12% were not given any prescription medication for COPD. More than 60% reported taking antibacterials for acute respiratory infections. Immunization rates against influenza and pneumonia were low, but higher for patients under the care of pulmonologists. Some

31% stated that they use oxygen regularly: 66% continually, 19% at night only, and 4% during exercise or when needed.

The physician portion of the NECA surveys, reinforced by the increased flow of anecdotal evidence from patients and physicians, as well as by clinical studies and reviews, indicated serious flaws in COPD management, which has made the disease what James Crapo, MD, of the National Jewish Medical and Research Center in Denver, CO, USA, calls "the largest uncontrolled epidemic of disease in the United States today."^[3] The *New York Times* article succinctly summarizes the problems: "[Experts] say chronic lung disease is misdiagnosed, neglected, improperly treated and stigmatized as self-induced, with patients made to feel they barely deserve help, because they smoked. The disease is mired in a bog of misconception and prejudice, doctors say. It is commonly mistaken for asthma, especially in women, and treated with the wrong drugs."^[3]

There is no cure for COPD, but anecdotal evidence indicates that a great many patients and quite a few doctors share the mistaken belief that there is no effective treatment for the disease, so there is no need to explore the available opportunities. The power of negative perception can be devastating. Smoking is, in great measure, responsible for COPD, but it also contributes to heart disease, among others, and yet the stigma does not extend beyond lung diseases. Comments of thousands of people who have crossed the path with my group over the years demonstrate that when first diagnosed, patients feel very vulnerable in a way that they have not done previously. Their self-image is altered. They feel confused and experience a loss of control. It is very important for physicians to reduce the magnification of symptoms by explaining the disease, offering available treatment options, and possibly engaging the patient's family or close friends. Physicians can help by recommending reliable sources of information such as books, internet sites, and patient support groups. The Joint Commission's 2007 white paper recommends a culture change to focus on patient-centered communication in order to make patients feel comfortable that they are not being blamed and shamed, and are being offered quality care.^[8] Sympathetic and understanding caregivers can build patient trust and confidence. This in turn will lead to better patient cooperation, better care, and early intervention with exacerbations – when they can be resolved more easily.

Patients with COPD are not optimally treated by physicians. The NECA physician survey showed that a sizeable number of physicians are in a 'blame and shame' mode and believe that "There is nothing that can be done for COPD patients who will not quit smoking."^[7] Clearly there is a need to pay more attention to well structured and effective smoking cessation programs. Some suggest that 'confrontational counseling' should be integrated into a state-of-the-art comprehensive program, involving face-to-face

counseling combined with pharmacological treatment.^[9] Patients expect their physicians to be well informed about COPD. In reality, only 55% of patients with COPD receive the care recommended in the GOLD guidelines.^[10] This is not very comforting, as this figure confirms earlier NECA survey findings, where the authors noted that the lack of familiarity with practice guidelines may have caused physicians to under-prescribe well tolerated, effective therapies and to inappropriately use predominantly ineffective therapies, such as long-term systemic corticosteroids.^[7]

The importance of these findings cannot be overstated. COPD is about difficulty breathing, exacerbations, and loss of ability to participate in life. It makes people miserable and disabled. Consequently, anxiety and depression are common among patients who have a difficult time adjusting to negative quality-of-life outcomes (regardless of whether they are prescribed oxygen therapy).^[11,12] Doctors should go beyond prescribing anti-anxiety medications and antidepressants. They should explore ways to alleviate patients' fears and feeling of hopelessness. As Mrs Koppel stated in the *New York Times*, "This is a disease where people eventually fade away because they can no longer cope with life. My God, if you don't have breath, you don't have anything."^[3]

2. Ambulatory Oxygen Treatment

We know that ambulatory oxygen can help. And yet, 'wearing' oxygen for all activities, and carrying or pulling around oxygen canisters with a cannula up one's nose contributes to anxiety and depression. Patients who require ambulatory oxygen often find daily living and leisure activities quite challenging. Many find it very difficult to 'wear' oxygen in social settings, so they either stay home or risk going out without oxygen. According to the NECA survey, "Forty-five percent of primary care physicians and 38% of pulmonologists found it somewhat or very difficult to convince patients with COPD to use oxygen. Twenty-five percent of physicians reported problems obtaining lightweight oxygen equipment."^[7] Plenty of anecdotal evidence from hundreds of patients, and my own >10-year experience with oxygen therapy, indicates that doctors would be able to do much more for their patients if they educated themselves about the various oxygen systems available and by wisely tailoring the use of these systems to the needs of their patients. It is very important that they take the initiative in prescribing the right system for their patients, taking into account their daily activities, as well as leisure and social needs. They also must counsel patients on travel with oxygen, using various means of transportation. Too many patients stay home because they are afraid that they will run out of oxygen or travel unprepared, jeopardizing their own safety. Flying with oxygen needs to be given more attention, and patients in the

advanced stages of COPD must be alerted to the need to arrange for supplementary oxygen with the airline when appropriate. Oxygen therapy should require doctors to regularly monitor the use of oxygen by their patients and teach them how to properly titrate the flow of oxygen for maximal therapeutic effect. Patients should be encouraged to use reliable oximeters to monitor their oxygen saturations with various activities. The issue of oxygen therapy is particularly poignant today in view of the bills in the US Congress,^[13,14] which will cut home oxygen reimbursements and force a very poorly designed competitive bidding process on oxygen providers without giving proper consideration to important therapy and safety issues.

An important issue related to oxygen therapy and shortness of breath is sleep anxiety. A small study of ten COPD patients revealed nocturnal anxiety and fears of breathlessness and dying. The patients did not report much assistance from their doctors.^[15] This resonates with me personally as I have experienced it. I was receiving oxygen at night and using a continuous positive air pressure machine, but I had a fear of falling asleep and when I managed to doze off, I would wake up frightened, with my heart wildly pounding as if it would break out of my chest. This eventually dissipated without any medical intervention.

3. Pharmacological Treatment of Exacerbations

Exacerbations have a major impact on the quality of life of patients with COPD and yet, with the exception of tiotropium bromide, all therapeutic compounds used in the treatment of COPD have been designed to treat asthma (relaxing airway smooth muscle). They often help to reduce exacerbations, but have no effect on frequency, and they cannot prevent them.^[16] There is substantial evidence indicating the role of pathogenetic mechanisms in promoting inflammation in COPD. Therefore, more research is needed to determine specific targets for intervention.^[17,18] Reducing the frequency of exacerbations is of major importance, because even small reductions would confer large human and economic benefits.

Dyspnea and exacerbations in COPD are routinely treated with inhaled bronchodilators and corticosteroids, or combinations of both. The NECA survey established inconsistencies and failures in following the treatment guidelines by physicians. However, recent studies also indicate another area of concern for patients: the incorrect use of inhaler devices, which may have a substantial adverse impact on the effectiveness of the administered drug. One study of internal medicine residents established that while “76% of 239 residents correctly identified the medication indicated for the case; only 30% of them adequately performed the inhalation technique.”^[19] In another study it was also demonstrated that

“between 4% and 94% of patients, depending on the type of inhaler and method of assessment, do not use their inhalers correctly.”^[20] The major problem with the metered-dose inhalers is hand-eye coordination, while with the dry powder inhalers, it is important not to exhale into the inhaler. In both cases, patients with weak inspiratory muscles and arthritic fingers have additional problems with the devices. In my several decades of using a variety of inhalers I have experienced many frustrating moments. I do not recall good instructions from my doctors (almost exclusively pulmonologists) or their nurses or medical assistants. I have observed hundreds of patients in various settings (even in the US Congress) who are unaware that they are using their inhalers incorrectly.

4. Pulmonary Rehabilitation Programs

It has been established that a pulmonary rehabilitation program must be an integral part of effective management of COPD, particularly in patients with moderate and severe stages of disease.^[21,22] From the patient’s perspective, an effective pulmonary rehabilitation program must provide disease education, instruction on proper breathing techniques, management of exacerbations and medications (particularly inhalers), individually tailored and monitored exercise routines, psychosocial support, and assistance with welfare and benefits systems. Instructions should be provided in layman’s language and oral presentations must be supplemented with written handouts. Currently, access to pulmonary rehabilitation is limited, partly because Medicare left the coverage decisions to individual states.^[23] It does not help that even, when the programs are available, they are under-used by physicians. The *New York Times* gives an example from the Washington, DC, USA area, where a patient with severe COPD had a mother in a pulmonary rehabilitation program, but her physician saw no need to send her to one, and instead focused on surgical options. Neither was such a program initially recommended to Mrs Koppel, who lives in the same area.^[3] Incidentally, we have five medical schools in the Washington, DC-Baltimore (MD) corridor, but none of them have an outpatient pulmonary program. The satellite hospital of the National Institutes of Health terminated such a program a few years ago after a very successful 11-year run. In the Washington, DC area there are now just four pulmonary rehabilitation programs to serve many thousands of COPD patients. There is hope that the bill recently passed by the US Congress^[14] will remedy the situation by providing Medicare coverage of pulmonary rehabilitation programs and allow for more programs to be set up throughout the country.

The scarcity of pulmonary rehabilitation programs also puts an undue burden on physicians. However, they may be helped by the

recent legislative Medicare Respiratory Therapy Initiative, recommended by the American Association for Respiratory Care.^[24] This congressional bill (H.R. 3968),^[25] already under consideration, will allow the placement of advanced-level registered respiratory therapists in physician offices, and thus provide patients with better quality healthcare. Similarly, physical therapists should be considered an integral part of pulmonary rehabilitation programs. By using breathing training methods (diaphragmatic and pursed lips breathing), combined with body movements and physical activity, they can effectively assist patients in managing shortness of breath. This is particularly important in frail patients who, through a special program of limited exercise, can graduate to aerobic activities, which will strengthen their muscles as well as increase their endurance, and ultimately improve their functional capacity and lessen distressing symptoms.

5. Lack of Physician Input

Doctors point out that there is not enough time during the usual patient visit to delve into many aspects of the disease and concerns of patients. However, spending more time on initially explaining the diagnosis and treatment options will help to make the future visits shorter and more productive. One patient in my group offers the following suggestions, "One of the things I have found invaluable in working with my physicians is an agreed-upon method of contact – whether it's e-mail or a certain time that patients can call in or some other method. It's also helpful to have a written agreed-upon plan between the patient and physician as to what symptoms warrant specific steps – contact with medical provider, appointment with medical provider, visit to urgent care or ER. Of course, this plan has to be revised as the patient's condition changes, but it's very helpful to have the discussion and try to have something in writing that both parties agree upon."

6. Conclusions

Medical advances notwithstanding, most patients with COPD demand therapies that are more effective, cause fewer adverse effects, and minimize co-morbidities compared with existing interventions. The challenge for medical science and the pharmaceutical industry is to bring about a qualitative change in therapy for the acute exacerbations of COPD as well as to the perpetual shortness of breath, which has such a devastating effect on quality of life. It is very encouraging that the medical community is beginning to recognize this challenge and is moving towards treating patients with COPD as 'whole people.' That includes the recognition of sex-specific disease characteristics. The success of all of these efforts is dependent on the recognition of COPD as a national health priority.

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Correspondence: *Włodzimierz 'Vlady' Rozenbaum*, International Online Patient Support & Advocacy Group, 3210 N. Leisure World Blvd., No. 614, Silver Spring, MD 20906, USA.
E-mail: vlady.rita@verizon.net