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# Bridging the gap: the patient-doctor relationship

## Budujemy mosty w stosunkach pacjent-lekarz

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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'. This campaign is "finally moving [COPD] from obscurity to prominence" 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" [1]. 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 the patient spokesperson for the NHLBI awareness campaign calls fittingly "the Rodney Dangerfield of diseases". It gets no respect. Others say that "O" in COPD stands for "obscure" or "overlooked" [2]. 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 [3], 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: \$42 billion a year

already. COPD is also the second leading cause of disability in the United States [2, 4].

The Global Initiative for Chronic Obstructive Lung Disease (GOLD) offers the international community comprehensive standards for the diagnosis and treatment of COPD [5]. These standards focus on four components of COPD management: (1) assessment and monitoring of the disease; (2) reducing risk factors; (3) managing stable COPD by applying education, pharmacologic treatments, and nonpharmacologic treatments; and (4) 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 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.

### **The National Emphysema/ /COPD 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

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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" [6].

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 health care — 85% were somewhat or very satisfied; 14% somewhat or very dissatisfied; perhaps, surprisingly, among those patients who described their health poor or very poor, 85% were somewhat or very satisfied.
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 having not 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 antibiotics for acute respiratory infections. Immunization rates were low, but higher for patients' under pulmonologist's care. Some 31% stated 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, calls "the largest uncontrolled epidemic of disease in the United States today" [2]. The *Times* article referred to earlier summarizes succinctly 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" [2].

There is no cure for COPD, but anecdotal evidence indicates that 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 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 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, which focuses 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 [7]. 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 shows that a sizeable number of them are in the "blame and shame" mode and believe that "There is nothing that can be done for COPD patients who will not quit smoking" [6]. Clearly there is a need to pay more attention to well structured and effective smoking cessation programs. Some suggest "confrontational counseling" to be integrated into a state-of-the-art comprehensive program, involving

face-to-face counseling combined with pharmacological treatment [8]. Patients expect their physicians to be well informed about COPD. In reality only 55% of patients with COPD receive the care recommended in the guidelines [9]. 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 underprescribe safe, effective therapies and inappropriately use predominantly ineffective therapies, such as long term systemic corticosteroids [6].

The importance of these findings cannot be overstated. COPD is about difficulty breathing, exacerbations and loss of ability to participate in life. They make 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 whether they are prescribed oxygen therapy or not) [10, 11]. Doctors should go beyond prescribing anti-anxiety medications and antidepressants. They should explore ways to alleviate patients' fears and feeling of hopelessness. As a patient stated in the *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" [2].

### Ambulatory oxygen treatment

We know that ambulatory oxygen can help. And yet, 'wearing' oxygen for all activities, 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" [6]. Plenty of anecdotal evidence from hundreds of patients and my own more than ten-year experience with oxygen therapy indicate 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 their patients' needs. 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 bill in the United States Congress which will cut home oxygen reimbursements and force a very poorly designed competitive bidding program 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 find much assistance from their doctors [12]. 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 dose 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 (neither my pulmonologists nor cardiologists knew what to do about it).

### 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. They often help to reduce exacerbations, but have no effect on the frequency of such and they cannot prevent them [13]. 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 [14, 15]. 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 indicate also another area of concern for patients: their 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” [16]. And in another study it was demonstrated that “between 4% and 94% of patients, depending on the type of inhaler and method of assessment, do not use their inhalers correctly” [17]. With the metered-dose inhalers the major problem 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 some of our Congressmen) who use inhalers incorrectly without being aware of it.

### **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 [18, 19]. From the patient perspective an effective pulmonary rehabilitation program must provide the following: 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. It does not help that even when the programs are available, they are underused by physicians. The *Times* gives an example from the Washington, D.C. area, where a patient with severe COPD had a mother

in a pulmonary rehabilitation program, but her own physician saw no need to send her to one, and instead focused on surgical options.

The scarcity of pulmonary rehabilitation programs puts an undue burden on physicians. They may be helped, however, by the recent legislative Medicare Respiratory Therapy Initiative, recommended by the American Association for Respiratory Care. A congressional bill already under consideration, will allow the placement of advanced-level registered respiratory therapists in physician offices, and thus provide patients with better quality health care. 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.

### **Doctor-patient interactions**

Doctors point out that there is not enough time during the usual patient visit to delve into many aspects of the disease and patients' concerns. However, spending more time on initially explaining the diagnosis and treatment options will help to make the future visits shorter and more productive. British researchers noted that doctors often fail in key tasks in communication with patients: “Only half of the complaints and concerns of patients are likely to be elicited. Often doctors obtain little information about patients' perceptions of their problems or about the physical, emotional, and social impact of the problems. When doctors provide information they do so in an inflexible way and tend to ignore what individual patients wish to know. They pay little attention to checking how well patients have understood what they have been told. Less than half of psychological morbidity in patients is recognized. Often patients do not adhere to the treatment and advice that the doctor offers, and levels of patient satisfaction are variable” [20].

One patient in my group offered 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”.

While treatment of COPD has certainly improved over the years, the increasing mortality and morbidity require more attention to be paid to the palliative and end-of-life care for patients. These are closely linked to anxiety and depression, which are common among COPD patients, but, unfortunately, not well recognized and treated [21]. Anti-depressants can improve patient's mood, reduce dyspnea, and thus contribute to effective treatment and enhanced quality of life as well as more appropriately modify preferences with regard to end-of-life care. Good communication between the patients, their families, and physicians may facilitate well framed advance directives, which can ease the stress of family members and improve their care for dying relatives [21].

In the patient-doctor interactions of particular importance are the patient support and advocacy groups and their interactions with the medical community. For several decades such groups have been set up throughout the United States by the American Lung Association, hospitals, and community organizations. With the advent of the Internet and greater availability of computers patients have taken advantage of this technological revolution. COPD patients have a multitude of organizations on the Internet, ranging from a half a dozen to thousands of members. They are national and international in scope. Some patient groups look for treatment that promises a cure. Others align themselves with licensed and reputable medical professionals to learn more about the disease, diagnosis, and treatment options. COPD-ALERT [<http://www.copd-alert.com>] is in the latter category.

In the late 1990s, the American Thoracic Society and the American College of Chest Physicians made it possible for large patient support groups to interact with top experts in the field by inviting them to their national and regional conferences and even including patients on conference panels. In 2005, patients groups were invited to the Sixth Oxygen Consensus Conference in Denver, Colorado, to discuss oxygen therapy issues with clinicians, respiratory therapists, and equipment manufacturers. Some patient support groups have medical professionals as members. COPD-ALERT

has several distinguished pulmonary experts, including Professor Jan Zielinski. They help patients to get educated about the significance of their symptoms, medical tests, and treatment options. These interactions, which include exchange of experiences between patients, coupled with the access to the most current medical publications have a great impact on self-management of COPD and on communications of patients with their doctors. Significantly, the recognition of patient input led to selecting them to boards of directors of medical foundations and professional organizations, and to soliciting patient opinions by the federal regulatory and research agencies such as the Food and Drug Administration, the National Institutes of Health, and the Department of Transportation. Furthermore, COPD patients often accompany clinicians and respiratory therapists on their visits to congressional offices and government agencies.

## Conclusions

Medical advances notwithstanding, most patients with COPD demand therapies that are more effective, cause fewer adverse effects and minimize co-morbidities. 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 gender-specific disease characteristics. The success of all of these efforts is dependent on the recognition of COPD as a national health priority. A meaningful and effective partnership of doctors and patients will make it happen.

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