

## COPD patients' rights: Can they be won?

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The Yellow Emperor's classic textbook of internal medicine (Figure 1) and the Hippocratic (Figure 2) corpus of documents originated more than 2,000 years ago.

The Greek works were to serve as textbooks for practitioners, but their enduring value today is their moral and ethical concepts of physicians' behavior toward their patients (1-3).

The Yellow Emperor's work was a treatise on the philosophy of health and disease based on Taoist thought, but it also outlines how the physician must inquire about the patient's life and the patient's concerns and instruct the patient about healthy behaviors (4).

Both of these works have important philosophical dimensions, and the philosophy of medicine is always important for the practice of medicine, but I believe that the most important similarity between the two views of medical practice is the centrality of the patient's right to ethical health care.

However, patients' rights are not restricted to their interactions with physicians. Patients are part of families, communities, countries, and the world. Patients have a right to expect support for their health from society at large.

As the Executive Director of the International COPD Coalition (ICC), the global organization of COPD patient organizations, I have heard from COPD patients around the world that the treatment of COPD is often carried out without a concern for their preferences about care, its cost, or even the outcome of their care (5)!

In many countries, including my own, the United States, it appears that COPD patients are viewed more as a marketing opportunity for medical goods and services than as individuals with their own needs, preferences, and rights. Further, the

extreme commercialization of medicine that has occurred during the past 50 years in many countries has eroded physician-patient relationships and undermined the COPD patient's right to health care in favor of financial gain for the medical industry (6). Society at large has also diminished its support and understanding of COPD patients and of its obligation to prevent COPD where possible.

In response to these erosions of COPD patients' rights, the ICC has worked with its member and partnering organizations to develop a list of 7 essential COPD patient rights (Figure 3) that was endorsed by the ICC member organizations at its Rome meeting in 2009 (7). Because of the variations of cultural and financial conditions across different countries, these rights are stated in general terms so that specific actions can be considered based on individual countries' resources (8). Many national COPD patient organizations have endorsed and translated this COPD Patients' Bill of Rights and use it in their advocacy and dialogue with medical organizations, health ministries, and other government representatives. These rights are divided between responsibilities of caregivers and responsibilities of society itself, but in most cases these rights are a shared responsibility. As I list these 7 rights I will provide some information about the challenges patients face in making each of these rights a reality.

### COPD patients' right to early and accurate diagnosis

An important action that deserves special attention with regard to COPD diagnosis is the Chinese funding of COPD research in early COPD diagnosis. In most of the world, COPD patients are diagnosed only when they become very symptomatic at which time more than half of their lung function has been destroyed by the disease. In China, Prof. Nanshan Zhong and his colleagues have done studies in which they have succeeded in diagnosing COPD in its very early stages. They found that early COPD behaves differently than advanced COPD in that airway obstruction shows much greater reversibility in response to therapy and this provides an opportunity for vigorous therapy, emphasizing medications, smoking cessation, and reducing exposure to toxic inhalants (9). By working with

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Figure 1. The Yellow Emperor of China.



Figure 2. Statue of Hippocrates.

primary care physicians and community health authorities, the Chinese researchers believe that much better monitoring and diagnosis of high-risk patients to identify very early COPD is possible and that this, for the first time, could lead to a slowing of the damage to the lungs or even a restoration of the normal lung physiology with appropriate care (10).

Giving COPD patients and their physicians a strong hope for recovery could reverse the current pessimistic attitude toward the disease. More research is needed to verify these findings in early COPD, but it is clear that simply ordering expensive pulmonary function testing, treatments, and medications that do not affect patient outcomes is not enough. An essential feature of the early diagnostic approach is the use of simple peak flow meters or hand-held FEV1 meters (10). And the involvement of primary care doctors to closely monitor high-risk patients over time makes the identification of very early COPD possible. Early diagnosis may be essential in providing COPD patients with the right of effective therapy!

#### COPD patients' right for information and education about COPD

Too often in developed countries, clinical research studies look only at the effects of therapy on surrogate values. For example, in COPD they emphasize FEV1 measurements, which do not

correlate well with improved patient outcomes late in the disease (11,12). Often such therapies have high incidences of disabling side effects and are very expensive (11,12). Such studies frequently do not provide comparisons of different therapies or analysis of whether a particular benefit (eg, fewer exacerbations) can be obtained with one less expensive drug or whether several drugs are needed to obtain the benefit. Such approaches that neglect patient cost and patient outcomes seem to be designed by drug regulatory agencies to facilitate approval of new, expensive, and unnecessary therapies. The ICC urges drug regulatory agencies worldwide to focus on patient outcomes rather than effects on surrogate variables. It recommends that better information and education for COPD patients would improve COPD outcomes more than research that doesn't consider patients' views (7).

#### COPD patients' right to support and understanding

During the first half of the twentieth century, primary care medicine in its many forms predominated throughout the world. COPD patients were part of their communities and their doctors provided continuity and comprehensiveness of health care for them. However, since that time there has been a global increase in the prevalence of specialist physicians and a decrease

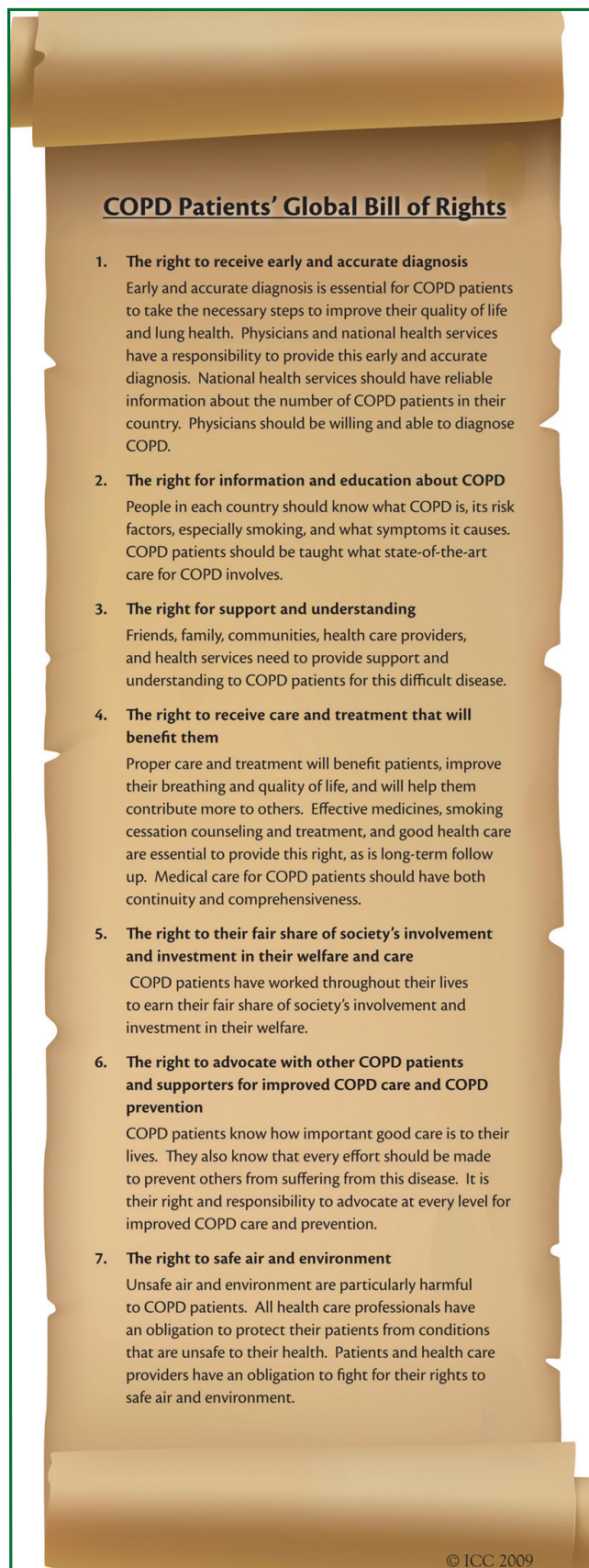


Figure 3. ICC's Global COPD Patients' Bill of Rights.

in the number of primary care physicians to the point that in many countries COPD patients have lost their access to their own family doctor, and with that lost many of their rights to continuity and comprehensiveness of health care. Community support and participation in COPD patient organizations can help to provide COPD patients' right to support and understanding.

### COPD patients' right to receive care and therapy that will benefit them

With the increase in specialty care, which often uses expensive high-tech methods, the expense of COPD patient care has increased substantially in most developed countries, with mean yearly COPD health care costs much greater today than in the past (13). The highest COPD care costs are in the United States, although many developed countries are also experiencing large health care cost increases (14,15). For patients without health insurance or unable to pay for care, their rights to therapy are seriously curtailed.

This increase in cost is difficult to understand, because between the days of my medical residency in the 1970's and today there has been little change in the therapy for COPD, both in outpatient and inpatient care: smoking cessation, bronchodilators, corticosteroids, antibiotics, oxygen, and chest physiotherapy remain the foundation. Evidence has not shown that life expectancy, co-morbidities, or activity limitations have changed during this time. What could account for the large increase in costs for the COPD patient if the treatments or their outcomes have not changed substantially?

After reviewing US COPD data in the NHLBI Chart Book (16) and discussing the financing of COPD care in the US with health economist Dr. David Armstrong, several points became clear. The cost of COPD care has risen about three-fold since the 1970's. Just from 2002 to 2009, direct and indirect costs in the US increased from 32.1 billion USD to 49.9 billion USD (16,17). This is a much larger increase than the overall increase in US cost of living during that time period; however, it is a similar increase to that of overall health care costs in the US. These high costs prevent many COPD patients from receiving care and the same can be said for many other serious diseases.

Coronary artery disease care in the US costs more than COPD care (16,17), but the improved results of therapy justify its additional cost. Morbidity, mortality, and prevalence of heart disease have been decreasing while COPD prevalence and morbidity have been steadily increasing. Improvements in the reduction of hyperlipidemia and high blood pressure, thrombolysis, bypass surgery, and coronary stenting procedures have all benefited cardiovascular patients, whereas there have been few improvements in COPD patient care or outcomes over the



past 40 years to justify the large increases in cost of their care. This unfair situation for COPD patients argues for efforts to lower the cost of COPD care and also to provide more funding for COPD research so that improvements in care may finally be achieved.

Because about 70% of direct costs for COPD in the US are related to hospitalization (16,17), one can surmise that the commercialization of health care in the US and the rapid increase in hospital care costs that it causes are responsible for the increasing financial burden on COPD patients and their families. The fact that little if any benefit in terms of COPD patient survival, prevention of the decline of lung function, or improved well being results from this care indicates that COPD patients are not greatly benefiting from it, which makes the increasing cost all the more onerous.

### **COPD patients' right to a fair share of society's involvement and investment**

In my opinion, it is the increasing commercialization of medical care in many countries that is largely responsible for the increasing costs. This situation is even more unfair for COPD patients because the escalation of cost often comes with little or no improvements in patient outcomes. It highlights how the health care system increasingly exploits patients, draining the patients' resources to enrich the health care industry that provides services to them (18). In some countries, such as the United States, there has been a dramatic increase in the number of middle class citizens who have been reduced to poverty by family health care costs, and the disparity between the incomes of the wealthiest members of the population and the rest of the population has dramatically increased (19,20). In addition, health care inequality based on racial, socio-economic, and other grounds has increased and represents a further handicap to certain COPD patients (21). I believe that these effects can be attributed, in part, to the over-commercialization of health care and the increasing wealth and power of the health care industry in many countries.

In some conditions such as atherosclerotic heart disease, new, expensive, high-tech techniques can be life-saving (22). However, when a large part of the funds for health care in a country are used to benefit elderly, wealthy patients and preventive care and funding of treatable fatal diseases throughout the population are ignored, the country's life expectancy, infant mortality, and burden of disease statistics will worsen. Expensive, high-tech care should not deprive a country from having preventive medicine and essential care available to the entire population.

The purpose of the COPD Patients' Bill of Rights (7) was to provide COPD patient organizations with a platform on which to lobby health ministries and health care systems. At the recent ICC World Conference of COPD Patient Organizations in Shanghai, the 480 attendees discussed the importance of finding role model

countries with respect to improving COPD prevention and care (10). The Health Ministry activities in China were of great interest. Their funding has facilitated a new approach to COPD diagnosis using low-dose CT scanning of the lung. It has proved to be accurate in diagnosing COPD even when only 10% of the lung has been impaired. These CT studies in China were performed for only 300 RMB (\$45 USD) per exam, although thoracic CT studies in Western countries are much more expensive. This Chinese research is a good example of an effort to develop ways to provide COPD patients their rights by implementing diagnosis and treatment that benefit them. Such research brings hope because it is targeted to improve patient outcomes.

There was agreement at the World Conference that China is an excellent model for national COPD efforts since it has acknowledged its serious problem with COPD, which most countries do have. According to current trends in China there will be twice the current mortality from COPD in 10 years! Because of this, China has taken strong and effective action to confront the problem. Accordingly, Prof. Jean Bousquet, the Chair of WHO's Global Alliance against Chronic Respiratory Diseases presented the ICC Achievement Award to Dr. Zhu Chen, Health Minister of China, for his vigorous efforts to confront both the causes and results of COPD (10).

### **COPD patients' right to advocate for improved COPD care and prevention**

A leader of global family practice organizations related a story from his own experience in which a 50-year-old man who was in medical training in the US developed a peculiar chest pain whenever he took a test. Uncertain as to how he should proceed with clinical evaluation of the pain, his attending physician presented the case to a psychiatrist, a cardiologist, a gastroenterologist, and an orthopedic surgeon. Each specialist recommended a thorough (expensive) work-up of the patient to look for the source of the pain in their own specialty's organ system, using the tests and procedures that they could perform.

This anecdote suggests that even among highly trained specialists, self interest can play a large role in medical decision making. Such commercial exploitation of patients deprives them of their rights to good health care. The primary objective of a patient's care should not be financial gain for their health care providers. Conflicts of interest (COI) such as this also have been found to affect the conclusions of experts participating in the development of clinical practice guidelines (CPG), and an approach to combat such COIs has been developed (23) using a WHO-approved method of assessing the conclusions of CPGs called the GRADE method (Figure 4). It involves a number of steps (Figure 5) to assess whether COI exists among the guideline participants and process, to ensure that costs are

**Table 1. ICC platform for COPD legislation.**

The International COPD Coalition calls on local, regional, and national governments around the world to implement the COPD Patients' Global Bill of Rights. Governments at all levels can take meaningful action to reduce the burden of COPD.

Legislation to address COPD should target multiple risk factors, and include prevention as well as treatment. Only a comprehensive COPD program can address all aspects of the problem synergistically. Rather than quick fixes, 5-year or other long-term, comprehensive plans should be developed. The ICC recommends that governments:

<p><b>Reduce exposure to COPD risk factors among all members of society:</b></p> <ul style="list-style-type: none"> <li>Expand tobacco control as rapidly as possible, including a multi-factorial effort to reduce secondhand smoke</li> <li>Institute a smoking ban in public places</li> <li>Reduce automobile emissions and exhaust</li> <li>Implement both technological advances and behavioral changes to reduce air pollution</li> <li>Reach those already at-risk with risk reduction messages</li> </ul>
<p><b>Support basic and clinical research to:</b></p> <ul style="list-style-type: none"> <li>Evaluate the effectiveness of COPD interventions</li> <li>Develop and implement new clinical techniques to benefit patients, improve activity, and reduce exacerbations</li> <li>Test blockers of oxidative stress in COPD</li> <li>Perfect inexpensive portable spirometry</li> <li>Understand the role of inflammation of COPD</li> </ul>
<p><b>Facilitate practical application of discoveries related to COPD in clinical care:</b></p> <ul style="list-style-type: none"> <li>Roll out carbocysteine mucolytic agents for COPD patients with chronic bronchitis</li> <li>Roll out peak flow meters and FEV1 meters for early COPD diagnosis</li> </ul>
<p><b>Ensure that COPD patients receive the care that they need:</b></p> <ul style="list-style-type: none"> <li>Enhance reimbursement for COPD management</li> <li>Enhance health insurance coverage of interventions related to COPD prevention, diagnosis, and treatment</li> </ul>
<p><b>Increase awareness and understanding of COPD:</b></p> <ul style="list-style-type: none"> <li>Support education of patients and the general population</li> </ul>

**GRADE**

Grading of  
Recommendations,  
Assessment,  
Development, and  
Evaluation

**Figure 4. Meaning of GRADE Acronym.**

considered, and to assure that patient preferences, adverse effects, and outcomes are considered (23). Because of these findings, the ICC has taken a position that it will not recommend any CPGs that did not include a GRADE analysis of its recommendations.

However, in the United States, COIs are not always considered to be a problem. Dr. Margaret Hamburg, Director of

**GRADE**

- globalizes guideline evidence
- focuses on important clinical questions
- considers cost
- considers patient outcomes
- conducts evidence reviews
- uses a common metric for quality of evidence
- considers co-morbidities
- helps guideline consumer implement guidelines
- deals with COI

**Figure 5. GRADE Process.**

the FDA, recommended that efforts to seat advisory committee members for FDA without COI was too difficult and should be abandoned (24). Here again, the patient's outcomes and welfare are not the primary considerations, the ease of the bureaucratic process is more important. Patient representatives are seldom or never included in the development of CPGs nor do they

play an important role in the decision making of regulatory organizations. This represents a serious abridgement of patients' right to advocate and an abuse of their right to care that benefits them. In the ICC's opinion, a diverse group of representatives: medical specialists, government health ministry representatives, COPD patients and their leaders, and primary care physicians, should all participate in developing CPGs, and those with COIs should not participate.

### COPD patients' right to safe air and environment

The wide range of government programs proposed, started, or expanded in China to address COPD became ICC's role model for COPD patient organizations in other countries to lobby their health ministries and governments. The programs in China include those listed in Table 1. Countries that implement or increase such programs within their countries deserve praise. For example, countries like China that act to implement new environmental protection laws are to be praised while countries like the United States, which repeals environmental protection laws, supposedly to stimulate business, deserve censure (Table 1) (25,26).

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