

A COPD PATIENT PERSPECTIVE: the need to build confidence and a positive outlook

Report from the International COPD Patients in Action (ICOPA) Taskforce

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FOREWORD

Breathing is central to being alive. Under normal conditions and through our life we take an average of about 20,000 breaths each day without even noticing. But people with chronic obstructive pulmonary disease (COPD) – an increasingly common chronic lung disease – are all too aware of each of these breaths because changes to their lungs mean that they can't breathe in and out properly. This makes it difficult, and eventually impossible, to go about everyday activities such as walking to the shops, climbing stairs and even cleaning and dressing. Try breathing in and out through a drinking straw and you will get some idea of what it is like to have COPD.

The fact is that COPD is a major cause of death and disability throughout the world (GOLD, 2006), and the numbers affected are increasing due to continued exposure to COPD risk factors and the changing age structure of the world's population (GOLD, 2006). The impact on the individuals affected, their families and health services is enormous (GOLD, 2006). Many people with COPD are undiagnosed and those that are diagnosed tend to be under-treated (Pauwels, 2004). A nihilistic attitude is pervading the prevention and management of the condition (Celli, 2006).

The good news is that there are many interventions that can help patients with the disease have better and longer lives. Stopping smoking and exposure to the other factors causing COPD can reduce the risk of developing the condition and its progression in those already affected. A range of drug treatments and other therapies, such as pulmonary rehabilitation, can reduce the symptoms of COPD and improve quality of life (Celli, 2006).

I agreed to chair the International COPD Patients in Action (ICOPA) Taskforce as I feel it is time that people know more about COPD and that health service providers take a more positive attitude to its diagnosis and treatment. The ICOPA Taskforce is a coalition of organisations from around the world which represent patients with COPD and their families.

I have worked closely with the Taskforce to develop this report and hope that it will help us to achieve our collective aim of raising awareness of the need for a more optimistic approach to COPD management and thus improve the outlook for the 600 million people living with COPD today (WHO, 2002), and the further millions at risk in the future.

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COPD is a slowly progressive lung disease

Damage to the airways in COPD, primarily due to tobacco smoking, causes them to become narrower and makes it harder to get air in and out of the lungs (British Lung Foundation, 2005a; Celli, 2006). People with COPD find it difficult to get their breath, particularly when carrying out daily activities such as walking (British Lung Foundation, 2005b). This is usually progressive over time. Although COPD primarily affects the lungs, it has significant effects on the rest of the body (GOLD, 2006).

COPD is common and increasing

There are an estimated 600 million people with COPD worldwide, making it one of the world's most common chronic diseases (WHO, 2002).

The number of people with COPD is growing because of the increasing use of tobacco, exposure to biomass fuels and people living longer (GOLD, 2006). Women are increasingly affected (Mannino, 2002; National Institute for Clinical Excellence and Health, 2004).

COPD kills more people each year than lung and breast cancer combined and is the only major cause of death that has an increasing death rate (National Institute for Clinical Excellence and Health, 2004).

COPD is a major cause of death

COPD is expected to become the third largest cause of death worldwide by 2020, exceeded only by heart disease and stroke (GOLD, 2006; Murray, 1996; Murray, 1997). Global mortality due to COPD is predicted to more than double by 2030 (Tashkin, 2004).

COPD has a major impact

It greatly limits activities and reduces quality of life. Nearly three out of four patients with COPD have difficulty with the simplest of everyday activities (Vermeire, 2002). The symptoms experienced by people with COPD can also have a psychological impact, with patients frequently experiencing feelings of anxiety, helplessness and depression (EFA, 2002).

COPD is costly

... for health services

COPD accounts for more than half of the total direct EU costs of respiratory disease (ERS, 2003). Annual healthcare expenditure for people with COPD is nearly 2.5 times that for people without COPD (Grasso, 1998).

... for people who have the condition

COPD is very costly in terms of the disability it causes, missed work, premature mortality and caregiver and family costs. It is the leading cause of lost workdays among respiratory diseases (ERS, 2003).

COPD is a chronic lung disease. Death and disability from COPD are considerable, and increasing. By the year 2020, COPD is predicted to become the third leading cause of death worldwide (exceeded only by heart attack and stroke) (Murray, 1996; Murray, 1997) and the fifth cause of disability (European Respiratory Society, 2003).

Efigênia's Story



The personal burden of living with COPD

Efigênia Glicério Felisbino was diagnosed with COPD in 2000 when she was admitted to hospital in São Paulo, Brazil because of shortness of breath. The personal burden of living with COPD hit Efigênia when she began to realise that she could not continue her daily activities such as walking, showering, and cleaning the house because she always had to stop and catch her breath.

The breathlessness that she would constantly experience made her anxious and afraid about her future and how she would cope with the disease. She became very depressed, not only because she was not able to do the activities she had once been able to do with ease but because the disease impacted on the lives of her family due to high medical costs and the need to contribute a vast amount of time and effort to help manage her condition.

COPD is under-recognised, under-acknowledged and under-treated (Pauwels, 2004). This could be due to a lack of recognition of the disease by healthcare professionals; patients' acceptance of symptoms as a natural consequence of ageing or smoking. COPD can be easily diagnosed with a simple spirometry test (Celli, 2006).

COPD is under-diagnosed

Fewer than half of people with COPD have a doctor's diagnosis (Mannino, 2002).

The seriousness of COPD is not fully acknowledged

People with COPD tend to under perceive the magnitude of their problem. They also tend to accept limitations associated with disease progression as natural for a person who has smoked (Rennard, 2002).

Patients' failure to acknowledge the seriousness of their COPD leads to underestimation of the problem by health services and policymakers and little advocacy for patients (Celli, 2006).

COPD is under-treated

An economic analysis of data from a large-scale international survey, 'Confronting COPD in North America and Europe,' found that up to 65% of patients did not receive regular prescribed medication and patients also reported poor symptom control and considerable use of healthcare resources (Wouters, 2003).

Grading COPD solely on the basis of lung function does not reflect the clinical manifestations of the disease and its prognosis

The severity of COPD is usually graded on the basis of lung function, and the benefits of treatment are often measured according to the improvement in lung function. However, it is inappropriate to assess the effects of treatment solely in terms of improvements in lung function because it is impossible to reverse a measure that is, according to the definition of COPD, not fully reversible (Celli, 2006).

It is no surprise, therefore, that the lack of large response in lung function to different therapies has resulted in a nihilism that is not deserved (Anthonisen, 1994; Rennard, 2002; Casaburi, 2002). However, treatment for COPD can result in significant benefits in terms of quality of life despite the irreversibility of lung damage (Celli, 2006; Calverley, 2007).

Gertrud's story



Neither Gertrud nor her doctor recognised that her persistent cough could have been a symptom of COPD

Gertrud Voigt is 56 years old. She first developed symptoms of COPD in 1982 when she developed a cough that would not go away but was not diagnosed with the condition until 21 years later.

Neither Gertrud nor her doctor recognised that her persistent cough could have been a symptom of COPD. However, in 2003 she was rushed into hospital experiencing major breathing difficulties and was told for the first time by a lung specialist that she had COPD. Even then, the details of the condition and the implications of the diagnosis were not made very clear to her.

After finally receiving her diagnosis, Gertrud was irritated that her condition had taken so long to be diagnosed. She joined a local COPD self-help group (<http://www.lungenemphysem-copd.com>) to find out more about her condition, and it was only then that she realised the seriousness of the disease.

Gertrud's COPD is currently under control and she is optimistic about her future. She had made the choice to live every day to its fullest and is looking forward to watching her daughters growing up.

Gertrud recommends all COPD patients continue to live their lives as normally as possible.

Bill's story



"Carpe diem – seize the day" is Bill's approach to living with COPD

Bill Scowcroft's inspirational story shows what a positive approach and effective treatment can achieve. He was admitted to his local hospital, in Winnipeg, Canada, in July 2001 with pneumonia, a complication caused by his COPD. His condition became so serious that he was not expected to live. After being hospitalised for five months, including four in isolation (he contracted MRSA) – Bill had lost 40 pounds (18 kg) and was so weak he could not push the TV remote control button.

Bill made the decision to gain control of his condition. His wife Caroline says he decided to "live with COPD, rather than die from it." He began a self-initiated exercise regime and pulmonary rehabilitation.

After two months he resumed full-time work as Director of the Grain Research Laboratory for the Canadian Grain Commission, never taking a sick day before retiring at 66 and had no exacerbations requiring hospitalisation between 2001 and 2006.

Bill, now living in Canberra, Australia, continues to be very active despite being on permanent oxygen therapy. He exercises for 1-2 hours per day, eats nutritionally, enjoys gardening and playing in Scrabble tournaments. He writes about managing COPD and his professional interest in plant biotechnology and crop improvement.

COPD is not only preventable, but also treatable. Treatments are available to improve patients' symptoms (Celli, 2006).

Taking a more positive approach to COPD

The Global Initiative for Chronic Obstructive Lung Disease (GOLD) recently incorporated the phrase "preventable and treatable" in the definition of COPD, following the American Thoracic Society (ATS)/ European Respiratory Society (ERS) recommendations to present a positive outlook for patients, to encourage the healthcare community to take a more active role in developing programmes for COPD prevention, and to stimulate effective management programmes to treat those with the disease (GOLD, 2006).

Raising expectations of what can be achieved with treatment and rehabilitation

The overall goals of treatment for COPD are to prevent further deterioration in lung function, to alleviate symptoms, to improve quality of life and to treat complications as they arise (Pauwels, 2001; Celli, 2006).

The importance of smoking cessation

As smoking is the major cause of COPD, smoking cessation is the single most important therapeutic intervention that is effective in reducing the symptoms of COPD and preventing its onset (Mannino, 2002; Celli, 2006).

Therefore smoking cessation should be the cornerstone of COPD management for patients who still smoke (Rennard, 2002).

Improved knowledge about COPD treatment

Patients and healthcare professionals should be aware that a range of pharmacological and non-pharmacological interventions are available for reducing exacerbations and hospitalisations and improving symptoms, quality of life, exercise capacity and survival in COPD (Celli, 2006).

These include:

- Bronchodilators – alleviate symptoms, improve exercise tolerance, and improve quality of life. Guidelines advise that inhaled bronchodilators are central to the symptomatic management of COPD (GOLD, 2006). Bronchodilators include inhaled short and long-acting beta2-agonists (LABA), which cause bronchodilation by stimulating the beta2-receptors, and short and long-acting anticholinergics that block the action of acetylcholine at cholinergic receptors on smooth muscle cells (Calverley, 2003a; Stockley, 2006; Johnson, 2001)
- Anti-inflammatory therapy – corticosteroids may be beneficial in individual patients who continue to have symptoms while receiving adequate bronchodilator therapy (Celli, 2006). Inhaled corticosteroids (ICS) have been shown to reduce the rate of exacerbations and slow decline in health status in patients with COPD (Burge, 2000)
- Inhaled corticosteroid/long-acting beta2-agonist combinations – combination therapies combining inhaled corticosteroids and long-acting beta2-agonists are available for treatment in COPD. Combination therapy with ICS and LABA produces superior health outcomes compared with monotherapy in patients with COPD, improving lung function, health status and symptoms, while reducing inflammatory markers and the frequency of exacerbations and may improve survival (Calverley, 2003a; Calverley, 2003b; Szafranski, 2003; Sin, 2006; Calverley, 2007)
- Mucolytics – drugs designed to decrease the thickness and ‘stickiness’ of sputum to facilitate expectoration, have shown variable results in trials. A study of one of these drugs in the chronic management of bronchitis demonstrated symptomatic benefits (Petty, 1990)
- Antibiotics – have proven effective in patients with evidence of respiratory tract infection (for example pneumonia and some cases of chronic bronchitis) (Ambrose, 2001)
- Vaccination – against community-acquired infectious diseases such as influenza and pneumococcal pneumonia, helping to prevent these common infections and their complications in people with COPD (Nichol, 1999)
- Long-term oxygen therapy – can be beneficial in some people with COPD who develop low blood oxygen levels (British Lung Foundation, 2005a)
- Pulmonary rehabilitation – patients with COPD can find it difficult to move around or carry out normal daily activities without getting breathless. They may also find that they get tired very easily and often feel exhausted. Pulmonary rehabilitation includes individual physical exercise programmes that are proven to reduce dyspnoea, anxiety and depression, improve exercise capacity and quality of life, and may reduce hospitalisation (Wijkstra, 1994; Celli, 1995)
- Lung Volume Reduction Therapy (LVRT) – is a procedure to help people with severe emphysema. LVRT is not a cure for emphysema but can improve quality of life and can be an alternative to lung transplantation. The goal of this therapy is to reduce the size of the lungs by removing about 30% of the most diseased lung tissues so that the remaining healthier portion can perform better (American Lung Foundation, 2005)

Patient participation in management decisions

Once diagnosed, people with COPD should be encouraged to actively participate in the management of their disease. This concept of collaborative management may improve self-reliance and esteem. All patients should be encouraged to lead a healthy lifestyle and exercise regularly (Celli, 2006).

Treatment should be tailored to the individual needs of each patient

The impact of COPD on an individual patient depends on the severity of symptoms, systemic effects and any comorbidities the patients may have.

The overall approach to managing stable COPD should be individualised to address symptoms and improve quality of life (GOLD, 2006).

LET'S HELP PEOPLE WITH COPD GET THEIR BREATH BACK

Call to action

The ICOPA Taskforce calls on policy makers and healthcare providers throughout the world to adopt a more optimistic approach to COPD management and to improve the outlook for the 600 million people with COPD (WHO, 2002) and the further millions at risk for the future:

COPD is a chronic lung disease. Death and disability from COPD are considerable, and increasing. By the year 2020, COPD is predicted to become the third leading cause of death worldwide (exceeded only by heart attack and stroke) (Murray, 1996; Murray, 1997) and the fifth cause of disability (ERS, 2003).

Action

- COPD should be a higher priority for healthcare services and policy makers, in line with the major contribution it makes to mortality, morbidity and disability
- Efforts should be made to ensure that the public and healthcare professionals are better informed about COPD, so they are aware of the risk factors and symptoms of COPD and the availability of treatment
- Policies and services should be developed to improve the diagnosis and treatment of COPD and to reduce the impact of the disease on individuals affected and their families

COPD is under-recognised, under-acknowledged and under-treated (Pauwels, 2004). This could be due to a lack of recognition of the disease by healthcare professionals; patients' acceptance of symptoms as a natural consequence of ageing or smoking. COPD can be easily diagnosed with a simple spirometry test (Celli, 2006).

Action

- Implement education and training campaigns to ensure that the public and healthcare professionals are aware of the symptoms of COPD
- People with symptoms of COPD and exposure to risk factors for the disease should be encouraged to see their family doctor early and, where indicated, undergo spirometry testing to achieve a prompt diagnosis
- Ensure that people diagnosed with COPD receive appropriate treatment and are monitored on an ongoing basis, with their treatment modified accordingly

COPD is not only preventable, but also treatable. Treatments are available to improve patients' symptoms (Celli, 2006).

Action

- Develop and implement policies that take a positive approach towards the diagnosis and management of COPD, raising expectations of what can be achieved through prevention and treatment
- Educate healthcare professionals, people with COPD and their families to ensure they are aware of the range of treatments available
- Ensure that people with COPD are treated according to the latest evidence-based guidelines, tailored to individual needs and comorbidities
- Educate healthcare professionals, people with COPD and their families to adopt a healthy lifestyle and physical activity in order to reduce weight, improve circulation and lung function
- Optimise the research, development and use of newer and more effective therapies to reduce the contribution of COPD to poor world health
- Highlight the importance of smoking cessation in COPD management for patients who still smoke

WHAT CAN BE ACHIEVED?

A wide range of projects on COPD that have been developed by the member organisations of ICOPA demonstrate the scope of what can be achieved:

Publicity campaigns

The Associazione Italiana Pazienti BPCO has developed several major campaigns over the past three years focusing on promoting the prevention of respiratory disease and campaigning for the support of patients with COPD.

V Giornata Mondiale BPCO
15 Novembre 2006

La BPCO è una malattia dei **Bronchi** e dei **Polmoni Cronica Ostruttiva**

“Senza fiato... ma non soli!”

La Giornata Mondiale BPCO è promossa dal Progetto Mondiale GOLD di divulgazione delle Linee Guida per la diagnosi, la prevenzione ed il trattamento della Broncopneumopatia Cronica Ostruttiva in collaborazione con l'Organizzazione Mondiale di Sanità (OMS) www.goldcopd.it

Hai un parente, un familiare, un amico, un vicino di casa che soffre di BPCO?

**NON LASCIARLO SOLO
REGALAGLI UN PO' DEL TUO TEMPO**

Mercoledì 15 Novembre telefonagli, fagli compagnia, chiedigli di uscire insieme, accompagnalo a fare qualcosa che possa fargli piacere

Associazione Italiana Pazienti BPCO
Sede Legale: Unita G. C. di Pneumologia, Azienda C. O. S. Filippo Neri - Roma
Segreteria: 060551 - Via Galvani, 156 - 20151 Milano
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www.pazientibpco.it

The Australian Lung Foundation ran a COPD awareness campaign. A poster and video were developed for the general public focusing on the importance of people with symptoms of COPD visiting their doctor to take a lung function test to ascertain whether they have the condition.

Would this knock the wind out of you?

Do you:!

- Cough several times most days?
- Bring up phlegm or mucus most days?
- Get out of breath more easily than others your age?
- Are you over 45 years old?
- Are you a smoker or ex-smoker?

It isn't normal to be short of breath. If you answered yes to 3 or more of the above questions, speak with your doctor about a lung function test.

COPD or Chronic Obstructive Pulmonary Disease is a long term disease of the lungs that reduces airflow and chronic bronchitis affects up to 1 in 8 Australians aged 45 or over and often causes breathlessness.

THE AUSTRALIAN LUNG FOUNDATION

A national not-for-profit organisation that teaches the principles of lung health education. www.lungnet.com.au | 1800 654 301

The National Institute of Health (NIH) and the National Heart, Lung and Blood Institute (NHLBI) are running a national public awareness campaign in the USA on COPD.

The campaign is entitled 'Learn More Breathe Better' and is aiming to increase awareness and understanding of COPD and its risk factors as well as promoting the benefits of early diagnosis.

Education campaigns and materials

The COPD Foundation (US) and the Associazione Italiana Pazienti BPCO publish a series of free educational brochures to raise awareness of COPD and the resources available to patients.

BPCO

La forza del Respiro misura la Vita.
Se Bronchi e Polmoni sono stonati parla con il tuo medico.

una malattia dei Bronchi e dei Polmoni Cronica Ostruttiva

Magazines

COPD Digest is published by the COPD Foundation (US). The 32-page colour magazine is sent free-of-charge to anyone wishing to receive it. In addition, the Associazione Italiana Pazienti BPCO and the Australia Lung Foundation also publish regular newsletters.

Training days

The COPD Foundation (US) and the Australian Lung Foundation run regular COPD Education Days. These full day seminars, provided free-of-charge, feature leading medical professionals speaking on a variety of topics, including: What is COPD?, pulmonary rehabilitation and treatments for COPD, among many others. The COPD Foundation Critical Issues Workshops Series was established to provide a forum for the scientific community to address critical issues, including improved treatments and education.

Telephone helplines

A variety of patient organisations including the Norwegian Heart and Lung Association (LHL), the Australian Lung Foundation, the Associazione Italiana Pazienti BPCO and the COPD Foundation (US) have set up free helplines for patients, relatives and health professionals to offer information on a wide range of COPD issues.



Spirometry testing

The COPD Foundation (US) launched its first Mobile Awareness, Education and Spirometry Unit at the Washington D.C. Convention Center on January 13th and 14th, 2007. This mobile spirometry unit ("MSU") has created awareness among more than 500,000 individuals in Washington D.C., Dallas, Texas, three cities in Florida and has conducted over 6,500 free spirometry tests.



USEFUL RESOURCES

ICOPA Taskforce members

- Associazione Italiana Pazienti BPCO (Italy)
www.pazientibpco.it
- Australian Lung Foundation (Australia)
www.lungnet.org.au
- Comité National contre les Maladies Respiratoires (France)
www.lesouffle.org
- European Federation of Allergy and Airway Diseases Patients Associations (Europe) www.efanet.org
- International COPD Coalition (International)
www.internationalcopd.org
- COPD Foundation (US)
www.copdfoundation.org
- Alpha One Foundation (US)
www.alphaonefoundation.org

Recommended websites

World Health Organization (WHO) - Global Alliance against Chronic Respiratory Diseases (GARD)
(www.who.int/respiratory/gard/en)

Guidelines

GOLD guidelines (www.goldcopd.com)
ATS/ERS guidelines (www.thoracic.org)
The COPD-X plan: Australian and New Zealand guidelines for the management of chronic obstructive pulmonary disease 2007 (www.copdx.org.au)

ABOUT ICOPA

The ICOPA Taskforce is a coalition of patient organisations which came together with the common aim of calling for a more optimistic approach to the management of COPD.

The Taskforce, led by Professor Celli, was brought together in three Virtual Meetings to discuss and agree potential outputs for use in campaigning for a more optimistic approach to COPD.

Following the three Virtual Meetings, the Taskforce decided to develop a report and supporting template media materials for national scientific/patient organisations to use locally to raise awareness of the need for a more optimistic approach to COPD amongst relevant stakeholders including patients, physicians, governments, payers and the media.

The Taskforce members have full editorial control over the contents of the report.

GSK has provided a grant for all ICOPA Taskforce activities to date including financial support for the Taskforce members to participate in the virtual meetings as well as a medical writer to compile the report and an agency to act as secretariat.

For further information about GlaxoSmithKline's policy for working with patient organisations please visit http://www.gsk.com/responsibility/cr_issues/patient-organisations.htm

REPRESENTATIVES OF THE INTERNATIONAL COPD PATIENTS IN ACTION (ICOPA) TASKFORCE

