THE TRUE FACE OF THE SECOND LEADING CAUSE OF DEATH

SPECIAL REPORT | 13 - 30 NOV. 2017
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Life-threatening lung disease: Europe’s ‘unknown’ killer
Kadenbach MEP: Tobacco warnings should mention chronic obstructive pulmonary disease
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A cough never killed anyone? Chronic lung diseases rank as second largest killer
COPD is on the European Commission’s agenda, EU health chief says
According to the World Health Organisation (WHO), chronic obstructive pulmonary disease (COPD) is a lung disease that results in changes in several different parts of the respiratory system and lungs at the same time. But it is far more than just a 'smoker’s cough'.

Its main cause is the usual suspect: smoking or passive smoking. But indoor and outdoor air pollution also plays its role.

WHO warns that COPD is not simply a "smoker’s cough" but a life-threatening lung disease that may progressively lead to death.

In 2004, WHO estimated that 64 million people suffered from the disease and 3 million died from it. The UN body also predicted that COPD would become the third leading cause of death worldwide by 2030.

But a study published in the "Lancet Global Burden of Disease" last September showed that in 2015, 3.2 million people died from COPD worldwide, an increase of 11.6% compared with 1990 and it’s the second cause of death worldwide.

Often underdiagnosed, COPD’s symptoms include breathlessness and a chronic cough.

THE ECONOMIC BURDEN

In addition to the severe health impact, the economic burden is also enormous, according to estimates.

The EU pays a heavy price for respiratory diseases amounting to more than €380 billion annually, ranging from healthcare to lost production.

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The annual costs of healthcare and lost productivity particularly due to COPD are estimated at €48.4 billion.

Several lawmakers in the European Parliament have signed a declaration 2017 on chronic respiratory diseases, urging the Commission and Council to take immediate measure to address this critical situation, focusing on prevention, especially for smoking, and an early diagnosis.

At diagnosis level, MEPs stressed that respiratory education for medical students and primary care physicians should be strengthened as well as access for all diagnosed patients to reimbursed state-of-the-art therapy to be ensured.

“It is necessary to guarantee rehabilitation using any required multidisciplinary intervention to keep people in the workforce and in their own homes for as long as possible,” the MEPs pointed out.

Eva Kaili, a Greek MEP from the S&D group and one of the initiators of the declaration, said “we asked the Commission to boost research into the causes of chronic respiratory diseases as they account for more than 315,000 European deaths every year”.

“Diseases such as respiratory allergy, asthma, and chronic obstructive pulmonary diseases (COPD) cost more than €300 billion per year. We managed to gather 249 signatures from our fellow MEPs, but there is still work to do in order to achieve our target,” Kaili told EURACTIV, adding that the Parliament will work closely with the European Federation of Allergy and Airways Diseases Patients’ Associations (EFA) to prevent the onset of these diseases for future generations.

THE ROLE OF SCREENING

EFA President Mikaela Odemyr highlighted the role of COPD screening, claiming that it determines life expectancy in Europe.

“We are the affected patients and see many possibilities for the European Union to combat this disease. It is not just about our lives and families, which should be enough to act with determination, but also that COPD is an expensive, heavy and long disease that can be approached differently to support patients being active,” Odemyr noted.

“I think the EU has the capacity to gather best practices and promote a harmonised approach to tackle COPD, to promote minimum standards of care for any patient in the EU,” she concluded.
Progress has been made on tobacco products health warnings but the next round of graphic labelling should also mention the less-known chronic obstructive pulmonary disease (COPD), which happens to be the second cause of death worldwide, MEP Karin Kadenbach told EURACTIV.com. Karin Kadenbach is an Austrian member of the Group of the Progressive Alliance of Socialists and Democrats (S&D) in the European Parliament.

She spoke with EURACTIV’s Sarantis Michalopoulos.

**COPD is the second cause of death worldwide. Is Europe sufficiently addressing this critical situation? What could be done better? Does the Commission have a role to play?**

In Europe, we are conscious of the challenges posed by non-communicable diseases, like chronic respiratory diseases, but only a few countries have adopted national management plans for diseases like COPD.

COPD in Europe affects 1 in 10 people over 45 and it is among the 10 top causes of death in the European Union, varying from country to country. We need to rethink our healthcare systems to respond to the needs of patients with chronic respiratory diseases and I think the European Commission should take stock of the good examples that exist, and propose a white paper or a strategy guiding member states on what policies to consider preventing and managing diseases like COPD. Not only to ensure the EU in all policies approach, but also to warn about lethal but slow diseases like chronic respiratory diseases. The EU cannot afford the cost of inaction against COPD.

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Last year, you and some of your colleagues in the European Parliament signed a joint declaration on the issue. Has there been any development since then? Is the Parliament ready to take the initiative on COPD?

I proposed this written declaration on chronic respiratory diseases because I believe a public health issue like COPD needs to be an EU issue.

In 2016, COPD was the second cause of death worldwide, because of expanding smoking patterns and exposure to polluted ambient air from cooking, heating and harmful particles indoors, among other things.

The EU cannot hide behind the lack of health competence to act. We can adopt EU policies under our responsibility and positively affect COPD, like tobacco control measures, air pollutants levels, research, or healthy ageing policies.

Lost productivity due to COPD is enormous. How could this be addressed for COPD patients?

We want to keep people in the workforce but with an ageing population, this is becoming more difficult. In the case of COPD patients, the problem is their lungs can deteriorate very quickly, isolating them at home.

Although the damage caused by COPD cannot be repaired, I think the care planned for COPD patients has to focus on stopping the disease from progressing, with treatment, but also with complementary medicines like kinesiotherapy and psychology.

Access to these disciplines is unequal depending on the member state but research shows that it does work, so we should be prescribing them more often. We also need to facilitate patients remaining at work, as it has been demonstrated that having an active life decreases the level of severity of the disease, and reduces healthcare costs due to COPD.

Which countries perform better?

Although there is no great European performer in the field of COPD management, the European association representing COPD patients (efanet.org) has documented good practices at national level.

In Germany, Ireland and the UK, doctors are performing COPD screening lung tests in health check-ups, which is the very first step to fight the disease back. I think all countries should include spirometry for people at risk of developing COPD, like other patients are having an electrocardiogram or a mammography.

Austria – my own country –, Belgium, Poland, Portugal, Spain and Sweden, have been providing access to pulmonary rehabilitation and smoking cessation programmes for free. Professional support and reimbursement of treatment to quit smoking is a fundamental measure to decrease respiratory disease and while I encourage the other member states to adopt it, I would like to see a strong signal from the European Commission pointing out at these win-win measures to the member states.

Smoking is the main cause of COPD. Is the EU doing enough to protect public health? Do initiatives like plain packaging go in the right direction or do you believe other measures should be imposed?

At present, the EU has focused on decreasing tobacco consumption through marketing measures, but that doesn’t cut the problem off. Plain packaging (combined with graphic warnings) are definitely going in the right direction; but the next round of pictures for graphic warnings should also mention COPD, which is a disease that is not known enough by EU citizens.

Furthermore, we have the opportunity to reduce exposure to tobacco smoke among children, we did it for shared working spaces and restaurants, and we can move beyond banning smoking in other public spaces for children like Paris, where it is prohibited to smoke in public playgrounds, and parks.

Not only will it protect our lungs, but it will be in line with the WHO FCTC, the first-ever international health treaty mentioning the need for smoke-free places all around.
Three asks from EFA Patients on World COPD Day

On World COPD Day, Isabel Saraiva, Deputy Director of EFA Member RESPIRA, the Portuguese Association for People with COPD and other Chronic Respiratory Diseases, highlights the minimum standards of care COPD patients need: earlier diagnosis, smoking cessation programmes and pulmonary rehabilitation.
Patients’ leader: Reimbursed anti-smoking programmes are a way to kill COPD

By Sarantis Michalopoulos

Stricter rules on smoking, reimbursed anti-smoking programmes and smoke-free public places are among the ways to prevent chronic obstructive pulmonary disease (COPD) from being a public health crisis, says Mikaela Odemyr.

Mikaela Odemyr is the president of the European Federation of Allergy and Airways Diseases Patients’ Associations (EFA).

Odemyr spoke with EURACTIV’s Sarantis Michalopoulos.

What is the best way to strengthen prevention of COPD? Do you believe that the new rules introduced in the Tobacco Products Directive are enough?

There is no better COPD prevention that informing about the disease. Even if COPD affects one in ten adults over 40, many people do not know about it, and those who have heard about it connect it with smoking only, which is not always the case. COPD is a kind of a blame disease, meaning that it is your fault if you get it. However, the true face of people with COPD and their families is not like that.

The Tobacco Products Directive is an effective measure to control how tobacco is sold in the EU, but it is not enough to prevent COPD. If politicians do not think about COPD as a respiratory disease not only caused by tobacco but also things like bad air quality and that there are real people with potential behind the ‘problem’, then COPD will not be solved.

The only way to stop COPD from being a public health crisis is a targeted approach to reduce chronic respiratory disease, undoubtedly with stricter rules for tobacco and smoking, but also with resourced smoking cessation programmes to support...
quitting smoking, and measures to reduce occupation exposure to gases, fumes and smoke in the workplace, causing 15-20% of COPD cases. And to prevent specifically COPD we could have targeted air quality policies, not only addressing traffic and industrial emissions but also the establishment of smoke-free public places such as parks and beaches.

**What are the practical implications of COPD for patients?**

Life is possible with COPD! It is the quality of life that will vary depending on the stage of the disease. Its lack of oxygen, which is vital for all of us! COPD patients all feel breathless, because of the inflammation in the lungs that damages lung tissue and narrows the airways, making breathing progressively worse. Another major symptom is mucus, that makes you cough.

These together take your breath away and eat up your energy, affecting your whole life. It’s a vicious circle, with limited physical activity the body deteriorates, leading to the development not only of other chronic diseases like heart disease and diabetes but also to even severe depression. That’s why COPD patients need guided physical training and psychological support as much as they need medicines, oxygen therapy, and support to quit smoking.

**Your organisation focuses a lot on early diagnosis. How can this be achieved?**

Late diagnosis is literally cutting the wellbeing and life of COPD patients short. The earlier the diagnosis, the more chances they get to stop or slow the damage to the lungs. The good news is COPD can be spotted with a lung function test called spirometry.

The bad news is that in some EU countries spirometry tests are not prescribed easily, and education for interpretation of the results is often not sufficient. What is worse, smokers, ex-smokers, and others at risk of developing COPD do not systematically have spirometry tests in their health check-ups.

Even if the EU is a pioneer on new scanning and prediction techniques for accurate diagnosis and personalised medicine, these techniques are not yet available in ordinary practice. The reality is that we desperately need information campaigns about the disease, not only to prevent it but also to be alert about its symptoms and enable timely diagnosis and to encourage patients who already have it.

**You are pushing for a harmonised approach on EU level and better coordination among EU member states. What is the main challenge for that?**

Access to health disparities between EU countries is huge. At EFA we have been asking for a strong signal from the EU to be strategic with the prevention and care of chronic diseases, especially with the most lethal and costly ones like COPD. The main challenge is that our healthcare systems have been conceived to treat, more than to prevent, and to treat in the short term.

That is why emergency hospitalisations due to COPD decline less than expected. I think that in our era of chronic diseases, prevention and care should be planned to look
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not only at how the healthcare system will cover the needs, but also at how environment, research, and social policies can respond to the COPD epidemic.

Already one in three members of the European Parliament have shown their commitment earlier this year to adopt such an approach in the written declaration on chronic respiratory diseases, but that is not enough to have real action. I think the main challenge is to make COPD visible for politicians, starting with the numbers of affected people and cost, but also with the implications it has to our ageing societies and quality of life.

**What are the advantages of a better access to rehabilitation?**

A better quality of life! Physical exercise and rehabilitation are effective weapons patients have to combat COPD and recover from worsening episodes. When you have trouble breathing is a horrible feeling, like breathing through a straw.

Pulmonary physiotherapy allows COPD patients to get fit to go back to work, keep up with their lives and be independent. In Sweden, patients are directly addressed to a COPD school in hospital. Another problem is isolation. Physical exercise in groups can overcome that because COPD patients they can be out in the community, encouraged by others, and share about the disease like we have seen in our #COPDMove video series with patients. Rehabilitation and daily exercise should be a non-negotiable part of the treatment for COPD. It also reduces hospitalisations and exacerbations and most importantly, it is an empowering tool for patients to cope with COPD and self-manage.

**COPD is the second biggest “silent killer” worldwide. Why has it been neglected all these years?**

Many patients feel stigmatised because their COPD is mainly explained by smoking, so it is treated as a scary, miserable, blame disease. You call it a silent killer, and it really is, because of the stigma it poses to patients and the loneliness of dealing with it alone. Healthcare systems are not very well tooled to fully embrace COPD patients. But, we have come a long way in ten, twenty years when no-one had heard about COPD. We now need to tackle it head-on and give hope and life back to patients and their families.
EU’s approach to COPD remains focused on tobacco control

By Paola Tamma

Despite alarming figures, the European Commission does not plan specific targets or a harmonised approach for the prevention of chronic obstructive pulmonary disease (COPD). Instead, it says it will ensure tobacco control policies are properly implemented in the member states.

The emergence of COPD as the second largest killer in the world has raised concerns among health experts and patient organisations who have called for an EU-wide approach to tackle the situation.

The European Federation of Allergy and Airways Diseases Patients’ Associations (EFA) has been particularly vocal in demanding a better harmonisation of care standards for COPD patients by reinforcing preventive measures. That means including spirometry in general health check-ups and supporting patients’ rehabilitation and quit-smoking programmes across the EU.

EU member states have all committed to cutting mortality from non-communicable diseases or NDCs (including cancers, diabetes, cardiovascular diseases and COPD) by 25% by 2025 under the WHO’s global NCD action plan.

In the EU, however, health is a national prerogative under the responsibility of member states. The European Commission does not aim to create any new targets for individual diseases such as COPD.
but to “maximise joint efforts with the member states and stakeholders in reaching these global targets”, a Commission spokesperson told EURACTIV.com.

The EU executive does not intend to set specific targets or strategies to harmonise access to preventive care and rehabilitative treatment for COPD patients, or any other individual disease. The Commission’s main contribution in this area lies in the EU’s tobacco control policy.

In June, the Commission suggested a number of changes to EU tobacco legislation, including plain packaging and mandatory graphic health warnings, a ban on menthol and flavoured cigarettes, safety requirements for e-cigarettes, and the option to ban imports of non-complying tobacco products.

“The work with the member states to ensure that tobacco control policy in the EU is effective will continue,” a Commission spokesperson said.

UNEQUAL ACCESS

Chronic obstructive pulmonary diseases are the second largest killer in the world. With illegal levels of air pollution and smoking rates close to 20%, Europe is among the hardest hit regions – but for patients, access to treatment varies greatly.

COPD is not a single disease but an umbrella term for chronic lung diseases that reduce patients’ breathing capacity. By reducing oxygen flows, COPD affects all other organs and eventually leads to death.

According to the WHO, COPD is the second cause of death worldwide and killed 3 million people in 2015.

In Europe, approximately 1% to 4% of all adults suffer from it. The main known causes are tobacco smoking, but also indoor and outdoor air pollution, as well as occupational dust.

It is not only a major killer but a huge cost as well: the annual costs of healthcare and lost productivity specifically due to COPD are estimated at €48.4 billion.

Yet a survey of 19 EU member states carried out by the patients’ association EFA in 2013 found that prevention, access to care and rehabilitative treatment for patients with COPD varies greatly across member states.

Spirometry – a test of patients’ breathing capacity – can diagnose respiratory diseases like COPD and asthma at an early stage but it is normally only performed by specialist doctors.

General practitioner (GPs) are the first port of call for patients experiencing early symptoms. But they don’t use spirometry, mostly because they don’t receive extra pay for it. In addition, spirometry is not included in regular health check-ups.

Once diagnosed, patients’ access to treatment is also unequal: in all countries surveyed patients suffering from COPD have to pay a small fee for some services, although chronically ill patients are normally exempt.

But in some countries, like Italy and Finland, COPD is not recognised as a chronic disease, and patients may have to pay for treatment.

Chronically ill patients experience a reduction of their breathing capacity and would benefit from pulmonary rehabilitation practices that are scientifically proven to reduce the number of days spent in a hospital and prevent a worsening of their condition. They also help reduce anxiety and depression rates.

But pulmonary rehabilitation and quit-smoking schemes are not widespread, and they are free only in a minority of EU countries.

Health budgets are obviously at stake. But advocates say pulmonary rehabilitation doesn’t need to take up beds in hospitals: it can also be done by patients in the comfort of their home through the internet.

A recent study published by the.
A cough never killed anyone? Chronic lung diseases rank as second largest killer

By Paola Tamma

The idea of a cough being fatal brings up images of coal mining, hollow-cheeked children and Charles Dickens novels. But are we really past the time when a simple cough could kill you?

Unfortunately not. According to the WHO, chronic obstructive pulmonary diseases (COPD) are the second largest cause of death, killing 3.2 million people in 2015 alone. In Europe, between 1 and 4% of all adults suffer from COPD.

Causes range from smoking (including passive smoking), air pollution and occupational dusts and fumes. The effect is a persistent reduction of patients’ airflow capacity and its symptoms include breathlessness and chronic cough. But these rarely come alone.

CO-MORBIDITY

COPD patients are also at higher risk of stroke, due to a reduced flow of

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oxygen, and indeed heart diseases may be the final cause of death. Research also shows that COPD is often the antechamber of type 2 diabetes.

Patients with COP are limited in their daily life activities, and acute episodes of breathlessness can also trigger anxiety and depression. Mental illness in patients with COPD have devastating consequences on patients’ coping strategies, and evidence shows that mental health problems increase reliance on healthcare systems of COPD patients.

NEGATIVE FEEDBACK LOOP

On top of reinforcing the negative impacts of co-morbidity, COPD exerts a devastating economic burden as well.

A 2015 study found that breathlessness and airflow obstruction (symptoms of COPD) could predict future job instability. A survey in the UK found that 10% of respondents experiencing airflow obstruction quit their job, switched to part time or reported changing their working hours and activities at work for health reasons.

Not only can COPD put people out of work but also unemployment may have a negative impact on patient health, increasing the risk of co-morbidities and the death toll of COPD, in a negative feedback loop.

Research shows that patients with COPD are more likely to develop co-morbidities, experience more acute episodes and have to be hospitalised more frequently – therefore adding the indirect cost of unemployment to the direct cost of healthcare.

Estimates suggest the EU spends close to €50 billion on COPD alone, due to health costs and loss of productivity.

Keeping patients in employment would slow down the disease, and lead to lower healthcare costs.

The EU does not have a specific strategy on COPD but treats it as part of its action on non-communicable diseases.

Commenting on its action on non-communicable diseases, the EU executive said: “The current joint action on non-communicable disease works on the issue of preventing chronic conditions at the workplace and retention of or re-employment of persons with chronic conditions. Best practices will be selected and a toolkit for employers developed.”

In the first phase of its work on non-communicable disease, the EU worked on a training programme for managers of patients with co-morbidity, and a new care model for co-morbid patients, which it seeks to field-test starting from 2020.

TREATMENT AND PREVENTION

Many cases of COPD are preventable by quitting smoking at an early stage – and even chronic patients can achieve a better quality of life and reduce the risk of death by engaging in active lifestyles.

The majority of COPD cases become apparent after 40 or 50 years of age, and an “active ageing” approach can bring significant improvements by ensuring the patient stays active thus reducing the risk of exacerbation.

Some EU countries (Finland, the Czech Republic and Portugal) have specific, cost-effective COPD programs, and other such as the UK, France, and the Netherlands have developed integrated care pathways (IPS) that outline all steps of treatment to lead to an improved outcome for the patient.

However, a survey of 19 member states by patients association EFA found significant variations in terms of access to treatment and preventive care.

But because health policy is the responsibility of member states, the EU takes only a subsidiary role.

“Taking into account the responsibilities of the member states for the definition of their health policy, the Commission does not intend to shape specific strategies on harmonising access to preventive care and rehabilitative treatment for patients with COPD or any other individual diseases,” a Commission spokesperson said.
COPD is on the European Commission’s agenda, EU health chief says

By Sarantis Michalopoulos

Diagnosis tools like spirometry should be promoted in order to monitor lung systems and prevent the spreading of illness like chronic obstructive pulmonary disease (COPD), the second cause of death worldwide, the EU’s Health Commissioner Vytenis Andriukaitis told EURACTIV.com.

“I am promoting very much spirometry because it is a very cheap and good instrument. We have enough science, evidence showing that those results can help monitor the lung systems,” the Lithuanian Commissioner said.

The main advantage of these medical devices is that they help diagnose COPD early on, he explained.

“I count on the European network on prevention of pneumonic diseases and of course on the possibilities to once again raise the question on such a diagnostic tool, and enshrine them in the area of primary care,” he insisted.

The European Federation of Allergy and Airways Diseases Patients’ Associations (EFA) has been particularly vocal in demanding a better harmonisation of care standards for COPD patients by reinforcing preventive measures.

That means including spirometry in general health check-ups and supporting patients’ rehabilitation and quit-smoking programmes across the European Union.

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COPD patients lack oxygen so their respiration is like breathing through a straw, EFA explained. Depending on the progression of the disease, patients may not be able to do ordinary things like walking or even standing. For them, the lack of oxygen can soon become a spiral that affects their whole body. And the more time patients remain sedentary, the higher the risk of death.

Almost one to two out of 10 Europeans aged over 40 are COPD patients who generate €48.4 billion annually in EU healthcare cost.

Organisations highlight the need for patients to be empowered, with tools ranging from education about the disease to developing expertise and self-managing.

They argue that COPD patients should be able to decide for themselves about their treatment.

“COPD can be a scary and depressing diagnosis. Your life is turned upside down in that consultation. If healthcare professionals don’t have the time to explain that life is possible with COPD and that the disease may slow down from harming the lungs, patients can lose confidence and start isolating,” EFA Director Susanna Palkonen told EURACTIV.

She cited Sweden as an example, saying patients there are referred to COPD schools where they learn about the disease. They can build their own coping strategies and meet other patients and healthcare professionals who support them and motivate them.

“It’s about patient empowerment, giving patients the power to fight COPD, through knowledge and informed choice of treatment. To breathe, to live, to work to enjoy. Each COPD patient will develop their own strategy but to get there, patients need to be in the driving seat to deal and move on with COPD. They need to feel the power that they are in control of their lives”, she explained.