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Chronic obstructive pulmonary disease in the awareness of Polish society. Report from the public opinion survey by the Polish Respiratory Society and TNS Polska

Przewlekła obturacyjna choroba płuc w świadomości społeczeństwa polskiego.

Report z badań opinii publicznej Polskiego Towarzystwa Chorób Płuc i TNS Polska

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Abstract

Introduction: It is assumed that signs of chronic obstructive pulmonary disease (COPD) can be found in 9.3% subjects of more than 40 years of age in general population in Poland. The aim of the presented survey was to assess knowledge of COPD in adult general population in Poland.

Material and methods: The study was performed in June 2013 in a representative sample of 1,000 persons of at least 15 years of age in Poland, using standardized direct interview.

Results: In 2013 only 3% Polish people admitted they had ever heard of COPD and knew what the acronym meant. Further 11% persons admitted having heard the term but had no further knowledge of the subject. Thus, the total of 14% persons in general population had previously heard of COPD albeit superficially. This figure is slightly higher as compared to the study performed in 2004. The second part of the study was performed in patients with COPD. Patients perceive the disease as a limiting factor in their daily lives, including negative impact on physical activity, causing loss of physical attractiveness (more often reported by women) or hurting their image of a strong and caring person (more often reported by men). The disease demands re-evaluation of the previous lifestyle, alienates patients from other people, and generates financial burden. Half of the entire studied general population either does not have any associations concerning potential causes of COPD or report various erroneous connotations (e.g. excessive alcohol consumption as a cause of the disease). Even patients with COPD have a similar view on causes of the disease. Importantly, the study revealed that awareness of the disease in smokers does not essentially differ from that in general public. Half of the respondents admitted having no knowledge on prevention of COPD.

Conclusions: There is an urgent need for widespread public education on preventive measures. Study results support the need of educating both healthy subjects and patients with COPD as to how effectively reduce the risk of developing the disease. One third of all respondents has no assumptions in this regard (i.e. explicitly declares having no knowledge at all on the subject), and more than 40% subjects have various misconceptions. Educators should therefore spread information about the disease but also correct these misconceptions.

Key words: COPD, survey, COPD in public awareness

Pneumonol. Alergol. Pol. 2015; 83: 1–14

Streszczenie

Wstęp: Przyjmuje się, że w Polsce u 9,3% badanych powyżej 40. rż. obecne są cechy przewlekłej obturacyjnej choroby płuc (POChP). Celem obecnego badania opinii publicznej była ocena wiedzy ogółu dorosłych Polaków na temat tej choroby.

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Materiał i metody: Badanie zrealizowano w czerwcu 2013 roku przy zastosowaniu standaryzowanego wywiadu bezpośredniego przeprowadzonego w liczącej 1000 osób reprezentatywnej próbie ludności Polski w wieku co najmniej 15 lat.

Wyniki: W 2013 roku zaledwie 3% Polaków przyznało, że słyszało określenie POChP i wie, co ono oznacza. Kolejne 11% deklaroowało, że gdzieś się z nim spotkało, lecz nie wie, co ono oznacza. Tak więc o POChP słyszało, choćby bardzo powierzchownie, w sumie 14% społeczeństwa, czyli nieco więcej niż w 2004 roku. Druga część badania przeprowadzona wśród chorych na POChP pokazała, że postrzegają oni swoją chorobę jako przyczynę różnych ograniczeń aktywności, zwłaszcza sprawności fizycznej, utraty atrakcyjności cielesnej (częściej wśród kobiet) i wizerunku silnego, opiekuńczego człowieka (wśród mężczyzn). Przewlekła obturacyjna choroba płuc wymaga przewartościowania dotychczasowego życia, wyobcowuje spośród innych ludzi, generuje obciążenia finansowe. Ogółem połowa Polaków nie ma żadnych skojarzeń dotyczących potencjalnych przyczyn tej choroby, bądź ma różne błędne skojarzenia (np. nadmierne spożywanie alkoholu). Osoby chorujące na POChP w podobny sposób widzą jej przyczyny. Ważny jest ujawniony w badaniu fakt, że świadomość osób palących tytoń zasadniczo nie różni się od świadomości ogółu społeczeństwa w tym zakresie. Co druga osoba przyznaje, że nie wie, czy można zapobiegać wystąpieniu POChP.

Wnioski: Istnieje pilna potrzeba szerokiej edukacji profilaktycznej społeczeństwa, za którą przemawiają ustalenia dotyczące przekonań zarówno zdrowych, jak i chorych o tym, co może skutecznie zmniejszać ryzyko zachorowania na POChP. Co trzecia osoba nie ma tu żadnych przypuszczeń (wprost deklaruje, że nie wie), a ponad 40% wyraża różne błędne poglądy. Stąd ważnym wyzwaniem dla autorów komunikatów edukacyjnych jest nie tylko popularyzowanie informacji o chorobie, ale także potrzeba korygowania tych błędnych przekonań.

Słowa kluczowe: POChP, badanie opinii publicznej, POChP w świadomości społeczeństwa

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Introduction

Epidemiology of COPD

Chronic obstructive pulmonary disease (COPD) is one of the most common chronic non-infectious diseases, the prognosed incidence of which is going to systematically increase during the coming years [1]. Current projections show that COPD will become the third most common cause of death in 2020 as compared to sixth place in the statistics from 1990, if recent epidemiological trends remain unchanged worldwide [2]. These trends include decreasing mortality due to cardiovascular and infectious diseases, increasing smoking habit as well as progressing environmental pollution, especially in underdeveloped countries. Demographic aspect is also of importance, with increasing human longevity and thus growing amount of aged subjects prone to developing COPD. Prevalence of COPD varies in different studies, depending on methodology, lower age limit of the studied populations and representative character of the particular studied groups. The assumed prevalence of COPD in persons over 40 years of age, as confirmed by spirometric test, is 8.9% [3].

No epidemiological studies in groups representative for the general population have been performed as yet in Poland. Two recently published small Polish studies yielded contradictory results. One study found signs of COPD in 9.3% subjects of more than 40 years of age [4], whereas the other study found COPD in as many as 26% of the analysed population [5]. The disease affects more commonly men, with male:female ratio of 2:1. However, this difference is

currently disappearing, as smoking habit becomes equally widespread in both sexes. Chronic obstructive pulmonary disease is currently the most common lung disease in Poland, and the fourth most common cause of death after cardiovascular disease, malignancy and unexpected sudden death.

Mortality rate in COPD was 21/100,000 inhabitants in 2009, and has been growing during the last 30 years. In 1980, the respective index was 18.8/100,000 inhabitants. Surprisingly, mortality rate in COPD in Poland remains among the lowest in the entire Europe, despite one of the highest rates of tobacco smoking. It is likely that the disease is heavily underestimated as cause of death, as many patients with COPD are reported as having died due to cardiovascular pathology or lung cancer. This can concern as many as half of all COPD patient deaths. Epidemiological studies on COPD revealed that the disease had previously been diagnosed in less than 20% subjects, including mainly patients with severe or extremely advanced COPD. Approximately 80% of all Polish COPD patients are estimated to have mild or moderate disease, which often remains undiagnosed and untreated. Lack of preventive measures at early stages of the disease is one of the reasons for increasing prevalence of the severe form of COPD.

Public awareness of chronic obstructive pulmonary disease

How about public awareness of chronic obstructive pulmonary disease (COPD) then? The survey performed by TNS OBOP in 2004 revealed

that only 6% adult Polish people admitted knowledge of the disease name (or the acronym). It is therefore no surprise that 85% respondents did not have any knowledge of disease symptoms, and only 10% could associate COPD with dyspnoea and breathing difficulties. Two thirds of the study population did not suspect that untreated disease can lead to death. Only one percent of all respondents placed COPD among smoking-related diseases [7].

More data concerning this subject was obtained from a recent TNS survey, carried out in June 2013. The survey focused on knowledge of COPD among adults in in general population in Poland but also shed some light on disease perception among COPD patients.

Material and methods

The study was performed in June 2013, and consisted of two parts. The first part was a computer-assisted standardised direct interview conducted in a representative sample of 1,000

Polish people aged 15 years or more. Second part consisted of focused group interviews (4 groups of 6 persons) with patients having moderate or severe COPD for at least half a year.

Methodology of the quantitative study

Quantitative study involved a standardised survey based on an electronic questionnaire and direct interview at the respondent's home (CAPI – Computer Assisted Personal Interviewing). Study group included 1,000 persons in a quota-random sample, representative for persons of at least 15 years of age in Poland. Quota sampling included the following parameters for subject selection: sex, age, education, county and number of inhabitants in the home town/city. The study was carried out between 7th and 12th June 2013. Figure 1 presents group characteristics in the quantitative study.

Methodology of the qualitative study

Methodology and group characteristics in qualitative study are presented in Tables 1 and 2.

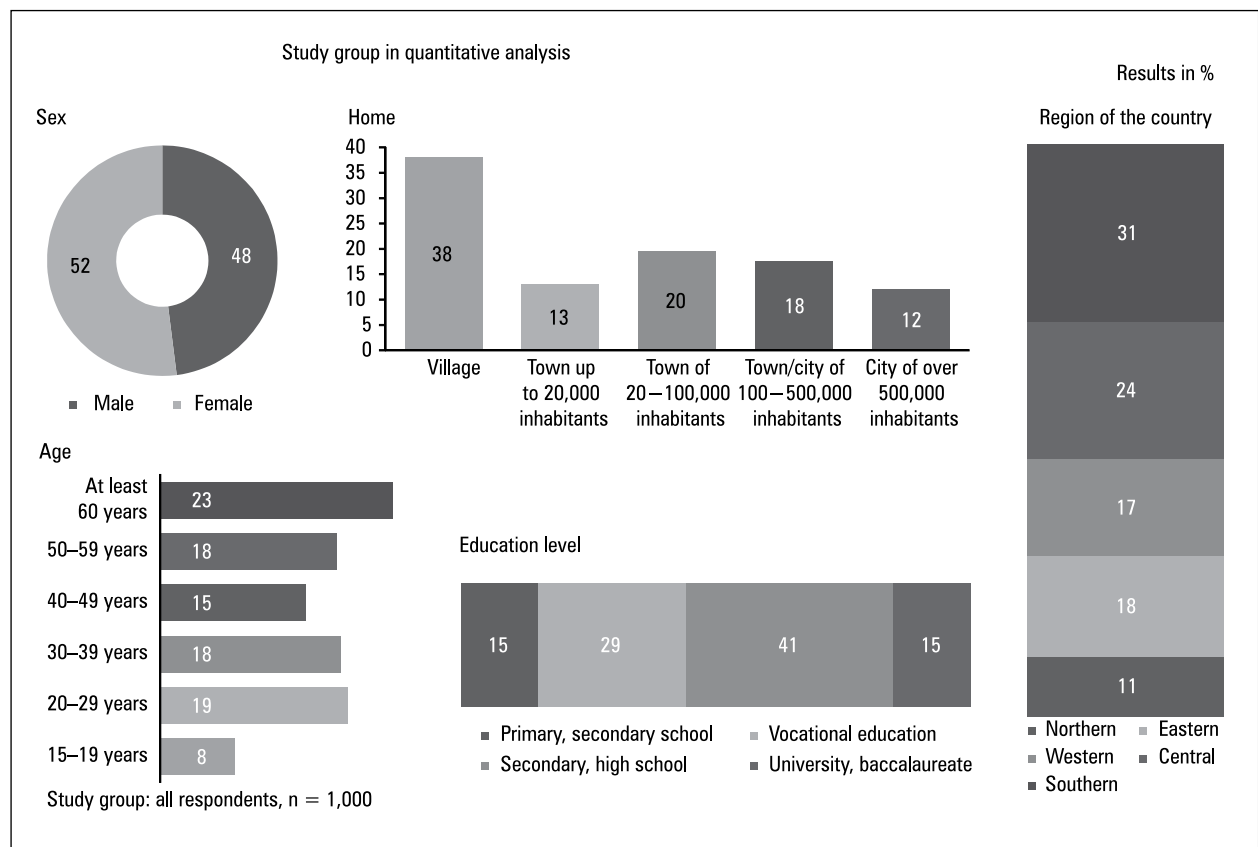


Figure 1. Group characteristics in quantitative study. Values as expressed in percent (%)

Table 1. Methodology of the qualitative study methodology

Location
<ul style="list-style-type: none"> ● big city: Warsaw ● smaller city/town: Piotrków Trybunalski
Respondents:
<ul style="list-style-type: none"> ● patients with COPD ● men and women (50/50%) ● age: 35–65 years ● disease duration of at least 6 months ● subjects professionally active or not working ● COPD of moderate (50% patients) or severe intensity (50% patients) ● variegated medical treatment (Alvesco®, Cortare®, Flixotide®, Miflonide®, Pulmicort®, Seretide®, Oxis®, Foradil®, Sym-bicort®, Spiriva®, Serevent®, Zafiron®, Singulair®, Oxodil®, Seebri®)
Method and sample size
<ul style="list-style-type: none"> ● 4 discussion groups (6 persons in each group, 2-hour-long sessions)
Research issues
<ul style="list-style-type: none"> ● patients' knowledge of the disease ● patients' attitude towards the disease ● COPD influence on patients' life ● experienced limitations because of COPD ● patients' needs and expectations of COPD treatment ● expectations towards physicians ● opinion concerning treatment/medication ● compliance

Results

What do Polish people know about COPD?

Chronic obstructive pulmonary disease is commonly referred to as COPD. In 2013 only three out of a hundred persons (3%) admitted having heard the name and knowing what the acronym means (Fig. 2A). Not more than half of all respondents could correctly explain the name of the disease (Fig. 2B). It can therefore be assumed that the term COPD is indeed known to roughly more than 1% of adult population in Poland.

Under ten years after the previous survey (from 2004), the term "COPD" began to come to public attention albeit very slowly. Up to 11% respondents declared in the current study having heard the term but still don't know what

Table 2. Study group in qualitative analysis

	Warsaw	Piotrków Trybunalski
Professionally active subjects	men/women aged 51–65 years	men/women aged 35–50 years
Subjects not working	men/women aged 51–65 years	men/women aged 35–50 years
Total of 4 discussion groups		

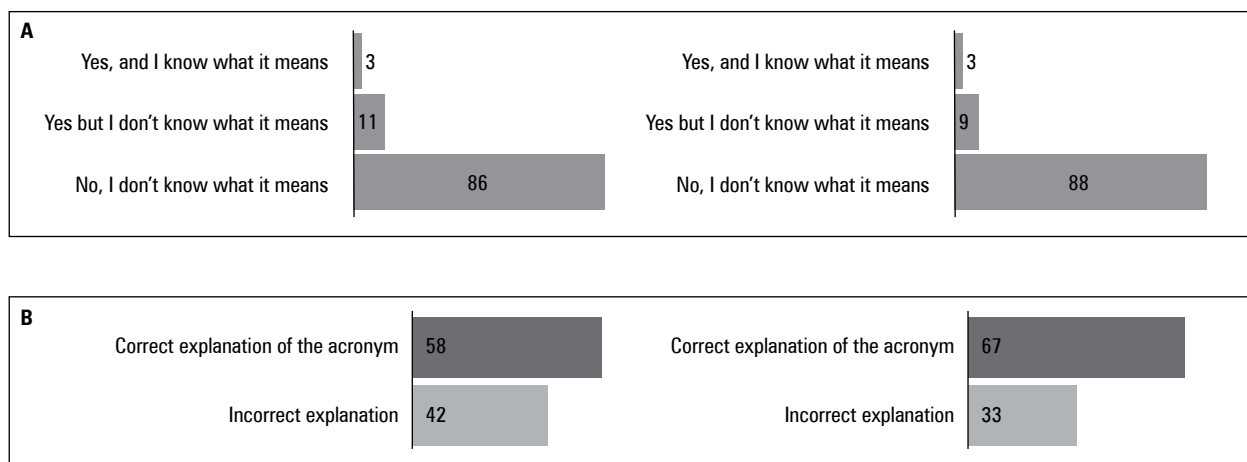


Figure 2. Obtained answers to the following question: Have you ever heard of COPD, and do you know what it means? Results are presented as percentage values. Vast majority of respondents (97%) did not know what the acronym COPD stands for. Almost 90% admits never having heard of this term. Results are similar in both smokers and non-smoking subjects (A); answers to the question "Please specify what COPD stands for?" Results are presented as percent value. Of all respondents who declared any knowledge of COPD, more than half subjects (58%) could correctly decipher the acronym. The respective value in smokers was higher (2/3) (B)

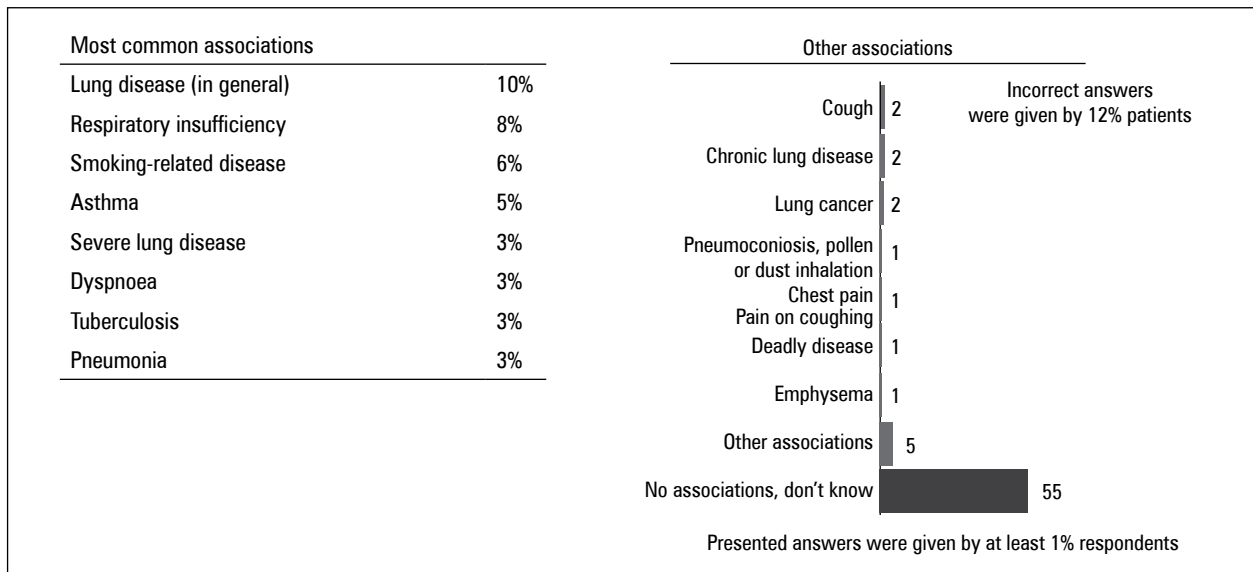


Figure 3. Obtained answer to the following question, in the entire respondent group: Do you know this disease? What associations do you have with this term? Results are presented as % values. More than half of Polish respondents (55%) had no associations with the term “chronic obstructive pulmonary disease”, and had no idea of the disease. Some respondents associate COPD with a lung disease (in general), others point to respiratory problems or a smoking-related disease

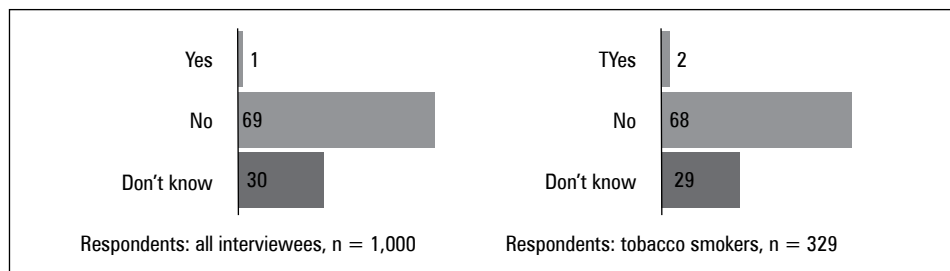


Figure 4. Obtained answers to the following question, in the entire respondent group: Do you or any of your relatives/colleagues have COPD? Results are presented as % values. On average, one third respondents (30% of all persons interviewed and 29% smokers) do not know if they have contact with any person having COPD. More than two thirds of all respondents (69% and 68%, respectively) claim to have no contact with any person affected by COPD

it stands for. The disease was acknowledged by 14% persons in the general public, which is a slightly higher figure as compared to results from 2004. Considering the impact of the disease, both on patients and on healthcare system, this awareness level remains still dramatically low, as 86% respondents in the current study have never heard of COPD. It should however be noted that during interviews respondents had a tendency of presenting themselves as “well-informed” to the anketeer, therefore the actual percentage of persons that have heard of COPD might be lower than reported.

For the vast majority of adults (more than ¾ in general population), the full name of chronic

obstructive pulmonary disease remains of low importance. More than half of all respondents (55%) have no associations with the acronym or can give the complete name of the disease. More than one tenth of the studied group (12%) have incorrect impression of the disease, and almost as many have only a general idea of the problem, i.e. that this is just a lung disease. Only few percent respondents could correctly name the disease and connect the name with right symptoms, risk factors or point to similar health problems (Fig. 3).

Scanty knowledge of COPD in the society has also a more abstract context, as respondents who have heard of the disease have no personal

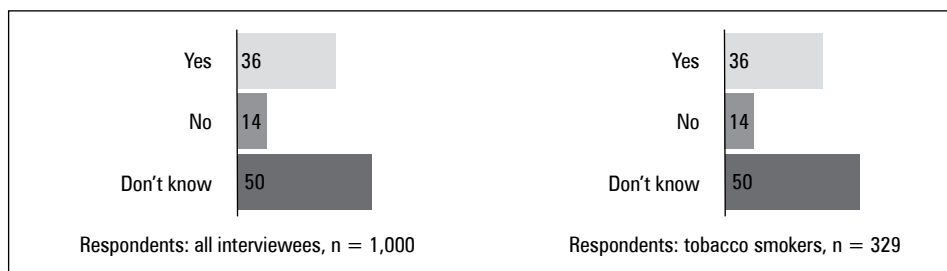


Figure 5. Obtained answers to the following question: Do you think that it is possible to prevent development of COPD? Results are presented as % values. Half of all respondents do not know if prevention of COPD is possible. One in every seven questioned persons (14%) claims that the disease cannot be prevented

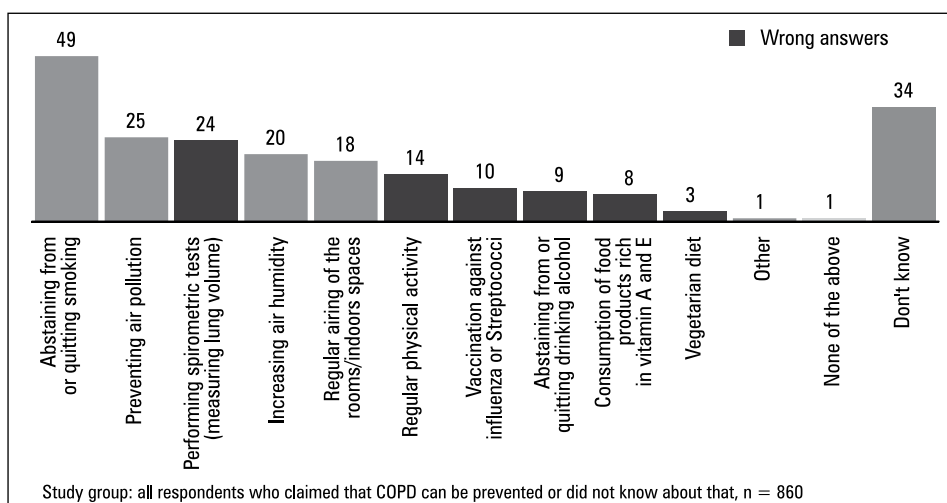


Figure 6. Obtained answers to the following question: In your opinion, what can efficiently decrease the risk of developing COPD? Results are presented as % values. Most respondents (49%) named abstaining from or quitting smoking as an efficient preventive measure, which can be explained by the previously mentioned association between smoking and risk of COPD. Of all other respondents, 42% gave wrong answers to the question

experience or direct contact with any affected persons, which could facilitate understanding of the problem, situation of the patients or make people care more about their own health status. Only one percent respondents declared having direct contact with a COPD patient (member of family, acquaintance) or being affected by it themselves (Fig. 4). If epidemiological data on disease prevalence is taken into account, at least several percent persons in the general public in Poland turn out to not know about the disease that they or their relatives actually have. This lack of awareness influences people’s attitudes and actions, as even many patients do not seek medical advice or treatment but also provide no psychosocial support to others by not considering their altered situation and increasing their level of stress.

Public awareness of COPD causes and prevention

It is apparent why half of all respondents did not know if any COPD prevention is possible, provided that only a minimal percentage of persons in general public have any knowledge of the disease (Fig. 5). More than one third respondents were optimistic as to disease prophylaxis, and one in every seven persons had a different opinion. Considered that respondents spoke about the disease that they actually have no real knowledge of, opinions concerning COPD prevention should be considered as sign of certain openness to future educative messages or preventive measures in 1/3 of the population rather than a sign of true knowledge. It can be expected that these persons could pay more attention to prevention campaigns or programmes, and can easier take in the message.

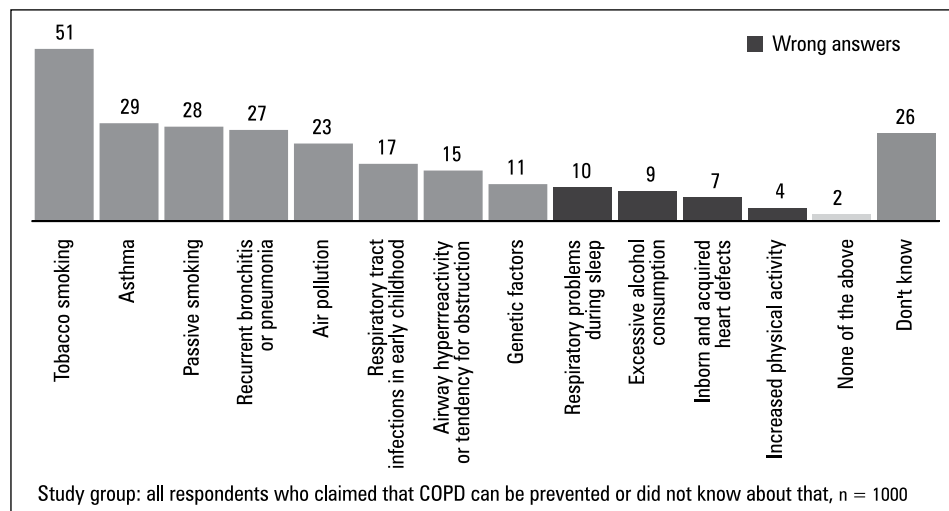


Figure 7. Obtained answers to the following question (all respondents): In your opinion, what can contribute to development of the disease? Results are presented as % values. More than half of all respondents in Poland claim that smoking habit is the main risk factor for developing COPD. Correct answers about causes of the disease were given by more than three fourths (78%) of all respondents

Need for education on preventive measures is clearly implied from the study results concerning methods of effective COPD prevention. One third of all 86% persons who think that the disease can be prevented, have no particular ideas or no knowledge of preventive measures, and over 40% of them have erroneous concepts (Fig. 6). Therefore, public educators should pay as much attention to informing general public of the disease as to correcting false beliefs, which might be even more challenging.

Even results concerning perception and ideas of risk factors and causes of COPD should be considered as an expression of individual attitude towards the disease and its prevention rather than expression of actual knowledge. Common perception is that COPD is related to tobacco smoking (including passive smoke inhalation) or previous diseases of the respiratory tract (asthma, recurrent bronchitis or pneumonia, infections of the respiratory tract during childhood), as reported by a smaller fraction of respondents. Correlation between COPD and air pollution was pointed out by almost every fourth respondent, and the role of genetic factors by one tenth of the studied group (Fig. 7). Still, half of all interviewed persons saw no possible associations between the disease and potential risk factors or had clearly erroneous ideas on the subject, e.g. naming alcohol overconsumption as risk factor of COPD.

Opinions concerning causes of COPD are similar in affected patients and in the general

public. Patients report association between COPD and previous diseases of the respiratory tract, some of which were improperly treated. They claim also the role of neglecting respiratory tract diseases, tobacco smoking and individual (inborn) susceptibility to diseases. Patients less often assume correlation between COPD and air pollution in their workplace or community. As compared to general public, patients affected by COPD tend to emphasise the role of genetic factors, which seems to represent a psychological defence mechanism of decreasing individual responsibility for the disease (Fig. 8).

The presented respondent profile can suggest that most persons in general public are open to messages concerning COPD preventive measures concerning tobacco smoking and, to a lesser extent, concerning respiratory tract diseases or air pollution. The opinion on tobacco smoking in public perception is a more complex issue, and will be discussed below.

Public perception of relationship between tobacco smoking and COPD

An important aspect of the study was revealing that awareness level in tobacco smokers (knowledge of the disease, impression of risk factors, attitude towards preventive measures) does not differ significantly from that of general public (Fig. 9). Smokers do have increased risk of developing COPD but at the same time

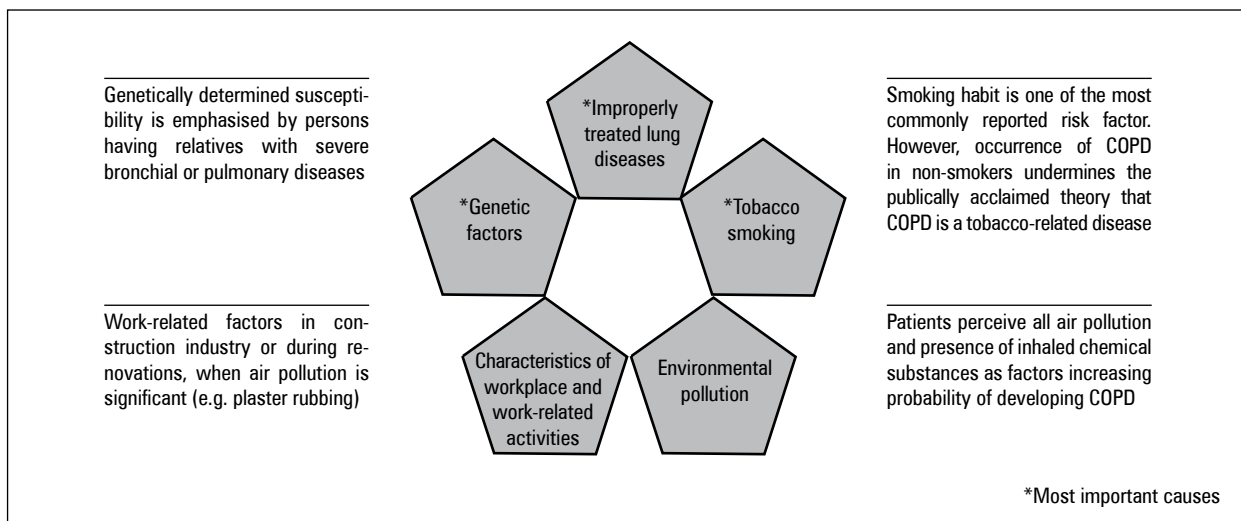


Figure 8. Causes of chronic obstructive pulmonary disease (COPD) as perceived by the affected patients

Most common associations		Other associations	
Lung disease (in general)	10%	Cough	2
Respiratory insufficiency	9%	Chronic lung disease	2
Smoking-related disease	5%	Lung cancer	2
Severe lung disease	4%	Pneumoconiosis, pollen or dust inhalation	1
Asthma	4%	Chest pain	1
Tuberculosis	4%	Pain on coughing	1
Pneumonia (lung inflammation)	3%	Deadly disease	1
		Emphysema	1
		Other associations	6
		No associations, don't know	53

Wrong answers were given by 12% respondents

Study group: tobacco smokers, n = 329. Multiple answers could be chosen. Presented answers were given by at least 1% respondents

Figure 9. Answers obtained from tobacco smokers given the following question: Do you know what kind of disease it is? What comes to your mind when you hear this name? Results are presented as % values. Answers in the smokers' group were similar to results in the entire study population. Respondents recognising the name of the disease (47%) most often pointed to symptoms and diseases of the respiratory tract

do not demonstrate attitudes or beliefs concerning COPD, which could lead to a healthier lifestyle.

Association between tobacco smoking and COPD occurs in public perception mostly when the role of smoking habit was previously suggested but rarely if this has not been emphasised.

When interviewees were presented with a suggestion that tobacco smoking can be one of the COPD causes, half of them accepted this idea. Moreover, smoking was the most com-

monly chosen risk factor from the entire list. At the same time, more than one fourth of all respondents claimed that even passive exposition to tobacco smoke can be a risk factor. Similarly, every second respondent admitted that quitting or abstaining from smoking may decrease risk of the disease when given such a suggestion. Avoiding tobacco smoke was the most commonly named preventive measure, followed by preventing air pollution, which was selected by half as many respondents (Fig. 10).

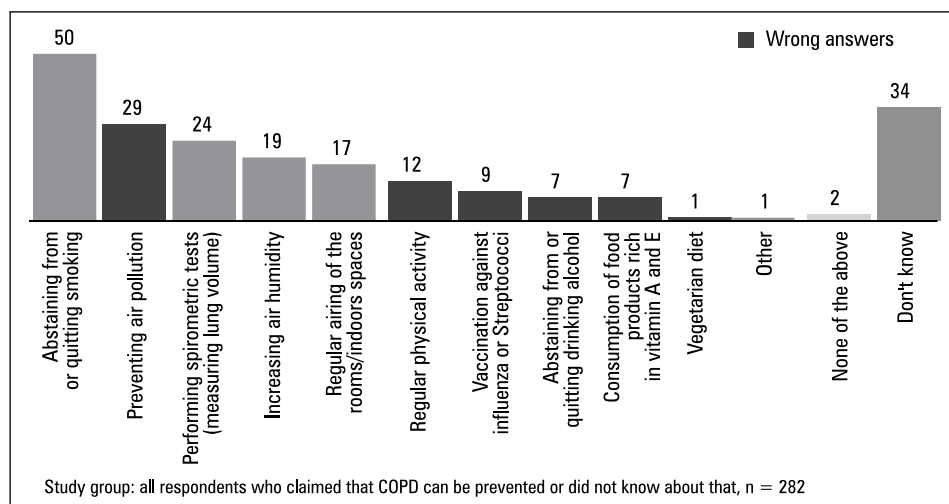


Figure 10. Answers obtained from smokers given the following question: In your opinion, what can efficiently decrease the risk of developing COPD? Results are presented as % values. Half of all smoking respondents in Poland (50%) named abstaining from or quitting smoking as an efficient preventive measure. Of all respondents, almost as many (42%) gave wrong answers to this question

Results revealed therefore that half of all respondents do not consider COPD as a smoking-related disease, despite having received such a suggestion.

On the other hand, when interviewees were not suggested that COPD can be related to tobacco smoking, not more than one in every twenty persons spontaneously had such an association.

Duality of the common perception of COPD and its relation to smoking most likely reflects general opinion on tobacco smoking. Smoking habit is commonly perceived as one of the most important factors affecting health status. At the same time, studies minimising the role of tobacco smoke are very popular, and thus might question reliability and authenticity of messengers communicating to general public [8].

As shown above, reservation is advised when interpreting quite an optimistic data, according to which half of the general population (including smokers) agrees to the role of smoking in development of COPD. Knowledge of the subject is a good starting point for promotion of anti-tobacco attitudes but is not enough to stimulate behavioural changes.

A similarly split perception can be observed in patients affected by COPD. Many of them accept tobacco smoking as an etiological factor of the disease but not necessarily as the main one. These subjects often have experience of meeting other COPD patients who never smoked but, still, developed the disease. These observations

undermine smoking as a first-line causative factor of COPD. That's why not all smokers diagnosed with COPD decide to quit smoking.

Why few COPD patients quit smoking — possible causes

Apart from the perception that tobacco smoke is not the only or a sufficient causative factor of COPD, there are also other reasons why tobacco smokers continue with the habit and do not quit despite being diagnosed with COPD. This is related to a strong dependence and impossibility to cope with the addiction. Patients demonstrate lack of faith and certainty as to the beneficial effects of giving up smoking. An important issue is also the relaxing effect and pleasure from smoking, which becomes an issue when the disease generates a strong discomfort and stress due to limitations encountered in daily life (Table 3).

Patient perception of doctor's attitude to quitting smoking is another aspect of great importance. Patients with COPD may notice that doctors play down their continued smoking habit. If doctors do not react to continuous smoking despite COPD diagnosis, patients assume that quitting is not that important for the course of treatment. On the contrary, patients meeting doctors who actively counteract and criticise smoking, more often try to quit or reduce smoking. Therefore, attitudes of the medical personnel play an important role in introducing preventive measures.

Table 3. Patient reactions following COPD diagnosis and recommendation to quit smoking

Continues smoking	Reduces smoking	Quits smoking
<ul style="list-style-type: none"> • Not all smokers decide to quit or reduce smoking • Smoking is a pleasure which I cannot deny myself, it helps me to become relaxed • Many long-time smokers declare will to quit if they can be assured that this could improve their health. However, they are aware that it is not going to be the case • Patients lack strong motivation from the doctor's part. Doctors know that patients continue to smoke but play it down. Patients feel then that quitting is not that important, if doctors do not react 	<ul style="list-style-type: none"> • Some smokers diagnosed with COPD who cannot quit the habit reduce the amount of smoked cigarettes • This attitude is a compromise between doctor's recommendation and retaining an important source of pleasure • Some smokers try to quit many times but are unable to remain smoking-free 	<ul style="list-style-type: none"> • Only few persons decide to give up smoking completely. This is related to: <ul style="list-style-type: none"> • difficulties with smoking. When respiratory capacity is low, smoking may become painful or not feasible at all • significantly decreased wellbeing after smoking a cigarette

Results of the current study suggest that COPD patients who decide to quit smoking do that not as a result of educational campaign or preventive measures (own knowledge and beliefs, acknowledged argumentation) but due to having experienced negative aspects of smoking themselves. This is related to physical inability to smoke anymore, pain on attempt to smoke due to reduced respiratory capacity or decreased unpleasant feeling after smoking a cigarette.

Personal observations and experiences of smokers diagnosed with COPD, including negative or positive impact of smoking and perception of doctors' attitudes should definitively be considered when developing preventive policies and planning anti-tobacco educational activities.

Relations between doctors and COPD patients

There is a prominent dualism in people's attitude to smoking, including opinions of the COPD patients but also in the attitude of patients towards medical personnel, including doctors. Physicians are authorities to many patients but their lack of confidence becomes apparent when considering results of the current study.

Survey among COPD patients revealed that reasons of patients' lacking confidence to doctors can be tracked back to the following experiences and opinions:

- doctors have limited capacities of making quick and correct diagnosis,
- doctors lack abilities to communicate with patients about the disease in a clear and understandable way, do not explain basic

concept and cause of the disease or use a complicated language that is hard to understand,

- appointments are short and "mechanical", with limited possibility for the patients to obtain information they need and expect.

Good communication between doctors and patients is especially important during first mutual meetings and when the final diagnosis has been made. Proper communication decreases patient's fear and reduces withdrawal reactions (negating the disease, playing down the diagnosis, lack of compliance). Of utmost importance is to communicate to the patient where and how further information on the disease can be obtained, how the lifestyle can be improved so as the patient is capable of better coping with the disease and counteract related negative emotions. Similarly important is communicating about treatment possibilities, including patient preferences, accessibility and individual situation.

Patient-doctor relation is a mutual one but most responsibility relies on the physician. Medical personnel, and in particular doctors, are the professionals responsible for patients' comfort in mutual relations but should also impose good compliance to medical recommendations. Therefore, personal authority is of great significance

Patient compliance

Patients with COPD are a heterogeneous population. Most of them are elderly, of a relatively low economic status, poorly educated physical workers, and having a general poor health status. These subjects have scanty

knowledge of their disease and therapy intentions but do not seek further information. Sociological studies reveal that these patients are not prone to modifications of their lifestyle. Another patient population including younger and more educated patients, who are well-off, work as specialists, managers or entrepreneurs, and are in good general condition, have also a much higher level of disease knowledge, are open to new information, therapy options and more willing to cooperate with medical personnel and modify their lifestyle. These patients are most likely to achieve better treatment outcomes but are relatively few in the whole COPD patient cohort. More attention should therefore be paid to the former patient fraction as they need mobilisation to cope with the disease and to comply with medical recommendations, whereas the latter fraction is more independent and demonstrates proactive and prohealthy attitudes.

Apart from quitting smoking, main recommendations given to COPD patients include taking medication regularly, which concerns in particular long-acting bronchodilators, and switching to a prohealthy lifestyle including proper diet, respiratory rehabilitation, avoiding getting cold and following vaccination recommendations.

Current survey revealed that many patients do not take medication regularly but become more compliant during disease exacerbations of when feeling worse. When symptoms disappear, patients stop obeying treatment rules, though. Taking drugs on a regular basis is generally perceived as an attribute of older age and grave disease, whereas the patients themselves do not feel like this. At the same time, particular prescribed drugs may make patients feel uncomfortable due to adverse effects, such as tachycardia or mouth dryness, duration of drug effect may be shorter than expected, treatment becomes costly and uncomfortable to apply or does not eliminate the disease but only alleviates the symptoms.

On the other hand, study results showed that patients' fear of disease progression makes them to comply with doctors' recommendations. However, disease-induced fear may have an adverse effect, as patients may cover up symptoms, avoid the subject and claim that "it is better to not know". Fear causes playing down health issues in COPD, leads to lack of

confidence and motivation to fight the disease and change lifestyle. It is therefore the doctor's role to tone down patient's fears so as to promote prohealthy modifications and not avoid them. However, the fear-of-the-disease card can be played so as to offer a more adapted treatment plan, which may decrease level of stress and anxiety.

As the current study revealed, patients' unwillingness to modify their lifestyles is mainly caused by lack of rapid noticeable positive treatment outcomes. Passive and negative attitude is more pronounced in patient groups of a lower socioeconomic status [9, 10]. Most preventive measures and strategies are not able to positively affect these factors, including socioeconomic status, social and cultural background and personality traits. However, beneficiary modifications can be obtained through good communication, with resultant reduction of patient anxiety and improved education of both affected patients and people in their surroundings.

Fear of the disease is generated by many different factors, of which the most important ones include:

- difficult and obscure name of the disease;
- feeling of anxiety due to insufficient communication with medical personnel, both when the diagnostic workup is carried out and when treatment is initiated;
- shortage of easily accessible essential information on COPD, coping with the disease and associated emotions;
- incurability of the disease ("lifelong disease");
- restrictions and limitations experienced during daily activities;

misperception of the patient by his/her surrounding, with social isolation and treating COPD patients as being "worse".

Living with COPD

Diagnosis of COPD affects patients' daily life, requiring lifestyle modification and acceptance of current and possible future limitations. Patient survey showed a common perception that the disease is a source of many limitations, including physical activity, decreased physical attractiveness (mostly perceived by women), and decomposition of the self-image of "a strong, healthy and caring person" (mostly perceived by men) (Table 4). Disease decreases confidence in capabilities of the own body

Table 4. Patients with COPD and their perception of own situation

Women with COPD (I feel so old)	Men with COPD (I cannot support my relatives anymore)
Strong impact of the disease upon self-confidence and perception of self-attractiveness	Feeling of deprived masculinity. Some patients admit feeling “not 100% male anymore” when diagnosis of COPD was made
Many patients feel disabled and older than they actually are, almost from the beginning of the disease	Fear and anxiety that with disease progression patients will become dependent on their relatives, whereas they should support their families themselves
Main factors influencing altered self-perception: <ul style="list-style-type: none"> • limitations in physical activity • constant fatigue during daily activities • necessity of taking medicines regularly • increased concern about one’s own health 	Young patients experience fear because of how their children perceive them and their disease. Patients fear they will not be able to raise their children the way they would like to. Besides, they fear not being able to promote the image of a “strong and healthy man who can cope with anything”, which is very much imprinted in Polish culture

and imposes rigorous treatment rules. It leads to modification of previous values, alienation from society, and becomes a financial burden. Stress arises upon contacts with other people, who may not have particular knowledge of the disease, becoming a major challenge for the patients

Difficult patient situation is further complicated by poor and superficial knowledge of COPD among patients themselves, as the survey shows. As the disease is associated with old age and death, patients experience generalized fear and anxiety. Besides, the name of the disease itself is difficult to memorise and understand both for the patients and for the general public.

Social alienation of patients with COPD

Lack of knowledge on COPD is common in the society, leading to the feeling of social alienation which patients experience and which has a bilateral character.

On the one hand, healthy patients will separate themselves from the sick as they associate cough with tuberculosis and want to avoid infection. Healthy persons may also marginalise the diseased and perceive them as handicapped or lacking in working efficiency.

On the other hand, patients separate themselves from healthy persons. Many patients with COPD are ashamed of the disease, neglect or hide it, treating it as an intimate subject, and avoiding speaking about own fears and limitations. Patients cannot efficiently communicate with other persons, apart from close family members, as their knowledge of the disease is limited, and their interlocutors are

not open, assertive or trained either. Patients tend to avoid public places and greater groups of people (densely populated areas, airless rooms, plane flights, company of smokers) as these situations may trigger symptom occurrence. At their workplaces, patients hide their symptoms fearing the reaction of the employer (risk of dismissal) and fellow workers (need to explain their situation, admit experiencing certain limitations).

Bilateral alienation of the patients has also adverse impact on their mechanisms of coping with the disease. Mechanisms of social support, which could motivate and improve both treatment outcomes and enhance preventive measures, are in such case disabled. These support strategies include initiating open dialog about the disease-related issues, promoting activities, enhancing and receiving assertive signals and confirmation that the disease is not a unique phenomenon.

Social support to patients with COPD may potentially come from two sources, from the patients’ families and from internet resources. Patients most often do not feel isolated in family settings and are not afraid to discuss particular disease-related issues, especially if other family members also have lung disease. Internet is an almost infinite source of information concerning the disease, with many easily accessible documents and offering a personal perspective (discussion fora, blogs). On the other hand, internet may also create a feeling of adherence to the patient community.

However, social support options are somehow limited as the network is currently avail-

able to not more than 2/3 of the society. Most COPD patients have unfortunately much less possibilities of using internet, as this population includes many elderly and less well-off persons, many of which are less educated. Digital competence in this population (capability of using different internet-related tools) and their health literacy (capability of taking into account and understanding the content of health-related documents) are relatively low.

Discussion

The above described results and their interpretation lead to conclusions important for constructing future strategies of COPD prevention.

1. Communication strategies concerning COPD-related issues should be addressed to the entire society. The messages should include information on the disease and its name, prevalence, symptoms and potential consequences of ignoring them, diagnostic measures, available methods of treatment and expected outcomes. An important issue is also emphasis on risk factors and preventive measures. Of utmost significance is how the messages are constructed, as they should be easy to understand, especially for persons of low socioeconomic status, and multifaceted, with input from both professionals and common people, in traditional and digital media and coming from both institutional and community sources. The messages should aim to familiarise the entire society with the disease-related issues but also to promote prophylactic measures. The latter aspect is of particular importance for tobacco smokers.
2. Educating medical personnel on COPD is crucial, and should concern in the first line general practitioners as they are an important educational link to the society, have an authority but should have as much competence in early detection and patient management. Therefore, postulated educational activities should include both the meritoric aspects (diagnostics, management) but also communication and motivational aspects, including promotion of quitting smoking, regular medication and lifestyle modifications. Of notice, these activities should promote a dialogue with the patient rather than an authoritative messaging.
3. All available measures should be taken into account in order to build and develop a social support platform for the patients with COPD. These should be aimed to stimulate and facilitate formation of open patient groups (offline, online) as well as promotion of discussing COPD-centred issues in public media. These activities may provide patients with peer-to-peer support but also emotional support in coping with disease-induced fear and anxiety.
4. Functioning of medical facilities should be improved. Specialist care for COPD patients, especially in smaller towns, and accessibility to diagnostic measures should be facilitated. Quality of service and facilities is valued low by the patients, and should thus be improved.
5. Furthermore, patients should have access to the most effective and easily applicable medication, which ideally should meet their needs and expectations. Treatment financing and reimbursement by National Health Fund (Narodowy Fundusz Zdrowia, NFZ) and social insurance companies are an important issue in this regard.
6. In the end, COPD prevention may be effective if it becomes socially widespread. Therefore, it should not only consist of individual campaigns but rather have form of a systematic, minutiously planned programme, involving mobilisation of various social groups for health promotion. Additional analyses may be required for this purpose, including evaluation of social needs and expectations, encountered limitations of preventive measures so far or possibilities of recruiting new collaborators. Chronic obstructive pulmonary disease-related issues should also be included in other health promoting campaigns and programmes.

Conflict of interest

PS received lecture honoraria from AstraZeneca, Boehringer Ingelheim, GlaxoSmith-Kline, Novartis, Pfizer, Polpharma, and Takeda. PS is a member of scientific advisory board for Almirall, AstraZeneca, Boehringer Ingelheim, GlaxoSmith-Kline, and Novartis. PS received also consultancy fees for clinical trials from Almirall, Chiesi, GSK, Novartis, and Takeda. KP declares no conflict of interests.

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