

**Introduction**

- Epidemiology of chronic obstructive pulmonary disease (COPD) continues to show an increasing steep trend in mortality<sup>1</sup>
- The acute exacerbations of COPD (AECOPD) remain the most relevant event impacting the mortality
- The timely treatment of AECOPD is clinically important; however, approx. 50% of exacerbations remain unreported and subsequently untreated<sup>2</sup>
- The exact definition of exacerbations is still controversial<sup>3</sup>, whereas the recognition of exacerbations and prompt action seem challenging for patients<sup>4</sup>

**Objectives**

- To understand the journey of patients with COPD, the exacerbations-related perceptions and behaviour and level of information directly from patients
- To develop targeted educational tools to assist healthcare professionals based on patients ‘reports

**Methods**

*Survey design*

- This was an online qualitative survey applied directly to patients from 4 countries (Austria, Canada, Romania and Spain) between 21-Oct-2020 to 19-Nov-2020
- A total of 305 COPD patients participated to the survey, 26% being from Romania (here we present the Romanian group results)

*Discussion guide development*

- The discussion guide was developed through a series of meetings with 7 National COPD Experts (3 from Romania), who provided input and advice on the questions and structure of the online discussion
- The following topics were covered: perception on health status, life before and with COPD, COPD exacerbations perceptions, actions and behavior, information level on disease, treatment, and uncovered needs, and attitude over disease and treatment

*Survey population*

- The survey was conducted among adult individuals (min. 18 years old), who confirmed that they had been diagnosed with COPD by a physician

**Results**

*Main patient characteristics*

- The group from Romania (N=80) included 58% (n=46) males, 26% (n=21) professionally active and 74% (n=59) retired participants
- The age distribution of the group was: 8% (n=10) between 35 - 49 years, 25% (n=20) between 50 - 59 years, and 63% (n=50) over 60 years old

*COPD journey*

- Initial symptoms at diagnosis: dyspnea, cough, reduced tolerance to effort
- First medical visit was to general practitioner (GP) or pulmonologist

**Table 1.** Patient profiles derived from the qualitative survey analysis

| Best descriptors                      | A. The optimistic  | B. The resigned  | C. The overwhelmed  | D. The laid back   |
|---------------------------------------|--|--|---|--|
| Age                                   | 60-65 years  | >65 years  | 50-55 years   | 40-45 years  |
| Professional status                   | Retired due to illness   | Retired due to illness   | Active  | Active   |
| Educational level                     | University   | Lower, blue collar   | University  | University   |
| Social support                        | Good   | Relatively good  | Poor  | Good   |
| Disease status                        | Moderate   | Moderate   | Advanced  | Early stage  |
| Adherence                             | Good adherence to treatment and lifestyle recommendations,   | Low adherence (on/off, based on symptoms), no giving up to smoking                                   | Likely to reduce adherence, has lost trust in treatment efficacy/doctors  | Relatively good adherence to treatment, active, despite not giving up smoking  |
| Level of information                  | Good: self and from doctors  | Little or no information, ignores the disease  | Relatively good   | Good: self, other relatives, and doctors   |
| Exacerbation perceptions and attitude | Aware of disease progression and irreversibility, fears exacerbations, avoid triggers, recognizes the onset of an exacerbation | Doesn't know what an exacerbation is, affirms he/she had no exacerbation despite persistent symptoms | Emotionally overwhelmed, fear of hospitalization, fear of death, social stigma, depressed, looks for alternatives | Confident (the disease doesn't worry the <i>laid back</i> ), optimistic, convinced that he/she will know how to deal in the eventuality of an exacerbation |

- Most bothering aspect of living with COPD: symptoms, treatment schedule and daily activities limitations

*Exacerbation insights*

- Half of COPD patients never heard of the term ‘exacerbations’, but were familiar with ‘worsening/flare-ups’, which were associated with disease progression and negative emotions
- Patients could not differentiate exacerbations by severity, and most could not recognize or self-treat an exacerbation
- A few patients were aware of means to prevent exacerbations (quit smoking, avoid exertion/polluted environments)

*Level of information*

- Most patients were content with their disease knowledge, but in fact they had little information on COPD
- In general patients were concerned by the need to be hospitalized during an exacerbation and require oxygen therapy during disease evolution
- The main sources of information: the treating pulmonologist or GP, and public websites

*Patient profiles*

- Four patient profiles emerged (**Table 1**):
  - The *optimistic*: good support system, educated and informed, good adherence, in control of COPD
  - The *resigned*: lower educational level, no knowledge

- of disease, low adherence, ignores the disease
- The *overwhelmed*: poor support system, informed, advanced stage, overwhelmed by disease/social stigma, low trust in treatment/physicians
- The *laid back*: young, early stage, active, good support system, informed, confident

*Educational tools derived*

- A visual aid based on COPD outcomes – the *Disease Map* – to help educate and engage patients in their disease management, based on their duration of disease (new vs. already known patients) (**Fig. 1A**)
  - Structured like game, it associated additional cards to discuss each major goal at various disease stages
  - It could be used individually or in group sessions
- An *Exacerbation Lexicon* including the real-life stories of patients participating in the survey (**Fig. 1B**)

**Conclusions**

- Recognition of an exacerbation – from terminology to management – and prompt action seem challenging for most COPD patients
- Various profiles of patients should be differently addressed to ensure disease and treatment knowledge and increase / maintain adherence
- Educational tools based on their specific needs may be useful in improving disease management

**Figure 1.** Educational tools derived: (A) the Disease Map, and (B) the Exacerbation Lexicon

