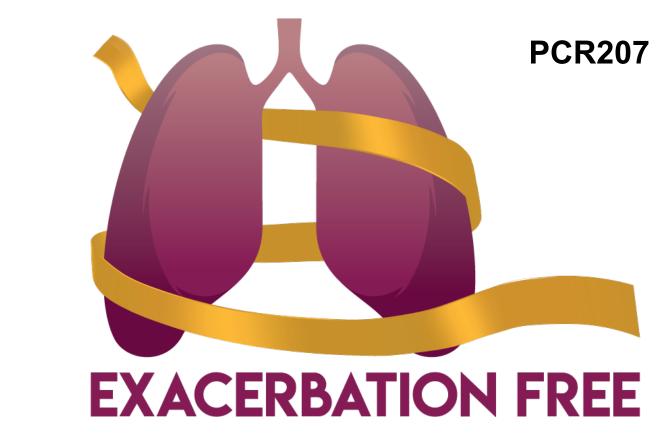
Exploring and Addressing the Educational Needs of COPD Patients Through a Multinational Qualitative Survey Focused on Exacerbations: Results of the Romanian Cohort (Exacerbation Free)

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Introduction

- Epidemiology of chronic obstructive pulmonary disease (COPD) continues to show an increasing steep trend in mortality¹
- 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 untreated²
- The exact definition of exacerbations is still controversial³, whereas the recognition of exacerbations and prompt action seem challenging for patients⁴

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/flareups', 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

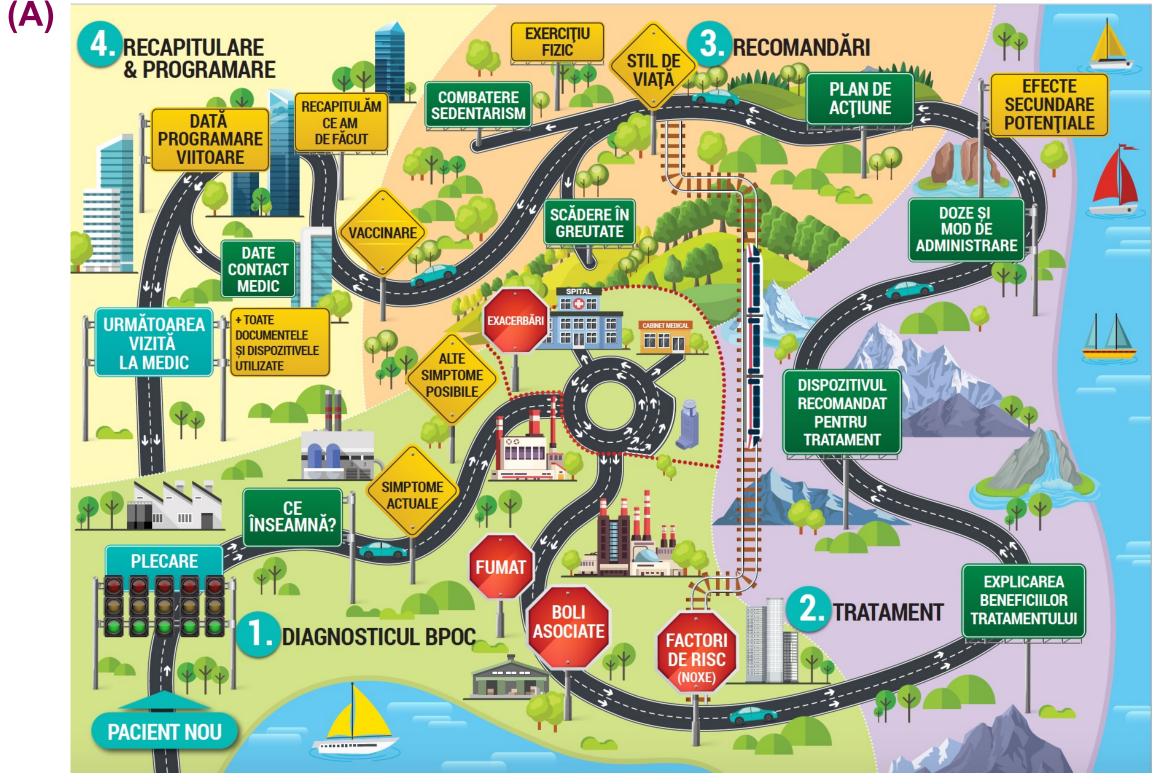
Educational tools derived

- 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











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