Original Research

Giving Voice to People – Experiences During Mild to Moderate Acute Exacerbations of COPD

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List of abbreviations: acute exacerbation of chronic obstructive pulmonary disease, AECOPD; pulmonary rehabilitation, PR; randomized controlled trial, RCT; Global Initiative for Chronic Obstructive Lung Disease, GOLD; body mass index, BMI; long-term oxygen therapy, LTOT; COPD assessment test, CAT

List of keywords: exacerbations; COPD; pulmonary rehabilitation; person-centred; qualitative research

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Note: This article has an online data supplement.
Abstract

**Background:** Acute exacerbations of chronic obstructive pulmonary disease (AECOPD) have a negative impact on health status and disease progression, but their clinical presentation is heterogenous. A comprehensive understanding of people’s experience during AECOPD is needed to develop person-centred interventions, such as pulmonary rehabilitation (PR). This study aimed to explore people’s experience during mild to moderate AECOPD, and their thoughts on PR during this period.

**Methods:** Short, semi-structured interviews were conducted with people with mild to moderate AECOPD treated in the community, within 48h of the diagnosis. Interviews were audio recorded, transcribed and analysed by deductive thematic analysis using the Web Qualitative Data Analysis software.

**Results:** Eleven people with AECOPD (9 male, 67±10 years, FEV₁ 41±16%predicted) participated. Four themes and seventeen subthemes were identified: impact of AECOPD (symptoms, physiological changes, limitations in activities of daily living, social constrains, psychological and emotional challenges, family disturbances); dealing with AECOPD ([not] depending on others, planning and compensation strategies); main needs during AECOPD (breath better, feel less tired, get rid of sputum, be able to walk); and (un)certainty about PR (lack of knowledge, get better, exercises, design and timing, trust in health professionals).

**Conclusion:** AECOPD, even when not requiring hospital admission, have a huge negative impact on people’s lives. People’s thoughts about PR reflect the need to raise awareness for this intervention during AECOPD. This study provides a foundation for the development of meaningful person-centred interventions during AECOPD.
Introduction

Acute exacerbations of chronic obstructive pulmonary disease (AECOPD) are defined as an acute worsening of respiratory symptoms that result in additional therapy $^{1,2}$. A recent proposal on an updated definition of AECOPD states that these events are characterized by dyspnea and/or cough and sputum that worsens over up to 14 days, possibly accompanied by tachypnea and/or tachycardia, and often associated with increased local and systemic inflammation $^3$. These events occur on average 0.5–4 times per person/year $^4,5$ and are a major cause of morbidity and mortality ($\approx 110,000$ deaths/year), accounting for 50–75% of all disease-related costs $^1,6-8$. AECOPD lead to a significant decline in people’s lung function, exercise performance and quality of life, and increase their susceptibility to subsequent AECOPD $^1,6,8$. The goals of treatment for AECOPD are therefore to minimize their impact and prevent the development of subsequent events $^1$.

Current management of AECOPD (e.g., pharmacological treatment) is only partly effective, and thus research on this topic is a well-established priority $^9$. AECOPD are heterogeneous in terms of pathobiological mechanisms, severity and clinical presentation, which leads to different prognoses, management needs and therapeutic strategies $^{10-13}$. People with COPD have reported the need for an increased understanding of the impact of AECOPD as it appears that physicians have been underestimating it, which may contribute to undertreatment $^{14}$. Nevertheless, previous studies have been more focused on people’s interpretation and recognition of an AECOPD than on the experience of the AECOPD itself $^{15-17}$. One study $^{14}$ explored the impacts of moderate AECOPD from people’s perspective, but its retrospective design (i.e., people recalling the exacerbation experience) might induce an important recall bias $^{18,19}$. Prospective studies on people with mild to moderate AECOPD are therefore needed, since understanding their symptoms, needs, experiences and feelings can potentially inform treatment strategies $^{20-22}$. 
Pulmonary rehabilitation (PR) is a well-established intervention for the management of stable COPD. Evidence for the use of PR in the management of people during and after AECOPD has been increasing recently. Nevertheless, quantitative studies have been mainly conducted in hospitalised people with AECOPD, when more than 80% of all AECOPD are managed on an outpatient basis (i.e., mild to moderate exacerbations), and qualitative studies have mainly focused in the period following the AECOPD. Moreover, people with AECOPD differ from those with stable disease, and currently there are no guidelines on how to conduct PR tailored to individuals’ needs and specificities during AECOPD. Listening to the perceptions of people during AECOPD, understanding their needs, concerns, goals and expectations is increasingly important to have them involved in a shared decision-making process, and to design and implement PR tailored to their preferences. This person-centred approach could improve the management of AECOPD and ensure its effectiveness. Thus, this qualitative study aimed to understand people’s experience (i.e., needs, impact, perceptions) during mild to moderate AECOPD. We also explored their thoughts on PR during AECOPD as a secondary aim.

Methods
This qualitative study was nested in a randomized controlled trial (RCT) evaluating the effectiveness of a PR programme during community-based AECOPD. The consolidated criteria for reporting qualitative research (COREQ) was followed. The ethic committees of the Health Sciences Research Unit: Nursing, Unidade Local de Saúde de Matosinhos, Centro Hospitalar do Baixo Vouga and Administração Regional de Saúde do Centro approved the study. Written informed consent was obtained from all participants prior to any data collection. A phenomenological approach was followed to gain a deeper understanding of the
phenomenon (i.e., AECOPD) through participants’ experience.  

Participants
A convenience sample was used. People with AECOPD were consecutively recruited from participants of the RCT between January 2019 and February 2020. People were eligible for the RCT if they were: i) diagnosed with AECOPD according to the Global Initiative for Chronic Obstructive Lung Disease (GOLD) criteria, i.e., presenting an acute worsening of respiratory symptoms that resulted in additional therapy (e.g., antibiotics, corticosteroids, bronchodilators); ii) included within 48h of the diagnosis; iii) managed on an outpatient basis and iv) able to provide informed consent. Exclusion criteria included: i) unstable cardiovascular disease; ii) significant musculoskeletal or neuromuscular impairment that precluded the performance of the tests or participation in PR (e.g., amputation, Parkinson’s disease); iii) signs of cognitive impairment; iv) current neoplasia or immunological disease and v) any therapeutic intervention in addition to standard of care (i.e., pharmacological treatment). All diagnosis of AECOPD were performed by clinicians at the hospitals and primary care centres involved in the study. At the time of the first COVID-19 lockdown, recruitment stopped since data from people with AECOPD during the pandemic could not be compared with previous data. The pandemic impacted on the number and severity of AECOPD and resulted in significant behavioural and social changes.

Data collection
Data collection were conducted at the Respiratory Research and Rehabilitation Laboratory – Lab3R or at participants’ own homes, according to their preference, within 48h of the diagnosis of an AECOPD, embedded in the baseline assessment for the RCT.

Sociodemographic (age, sex), anthropometric (body mass index [BMI]) and general clinical
data (smoking habits, number of self-reported exacerbations in the previous year, use of long-term oxygen therapy [LTOT] and non-invasive ventilation, and lung function – from clinical records) were first collected to characterise the sample. Severity of the AECOPD was classified according to the GOLD criteria. The COPD assessment test (CAT) was used to characterize the impact of the disease, as this is one of the key outcome measures recommended to assess this population and the one presenting more robust measurement properties during AECOPD. The total score can range from 0 to 40 and is interpreted as follows: <10 – “reduced impact”, 10-20 – “medium impact”, 21-30 – “high impact”, and >30 – “very high impact”. Then, short, semi-structured, face-to-face interviews were conducted. Semi-structured interviews with open-ended questions were chosen as this approach allows to gain an understanding of participants’ experience and the emergence of new topics that are important to them and have not been previously thought as relevant by the research team. A semi-structured interview guide (Table 1) informed by the literature, previous experience of the team, and an experienced qualitative researcher was built to ensure that the topics under investigation were covered in a consistent manner but allowed flexibility. The interview guide integrated questions about participants’ experience during AECOPD and their thoughts on PR. The interviews were audio recorded (Olympus digital voice recorder WS–750m) and transcribed verbatim, with participants’ names anonymized.

Please insert Table 1 here.

AM, physiotherapist (female, 28y, PhD student) contacted the participants for the study, led the qualitative interviews, transcribed them and was involved in the analysis. SA, gerontologist (female, 29y, PhD) reviewed the transcriptions and was involved in the analysis. CB, physiotherapist (male, 41y, senior researcher) and ASM, physiotherapist (female, 43y, senior researcher) reviewed the themes and coding and discussed them with AM and SA.
Data analysis

Descriptive statistics (i.e., absolute and relative frequencies, mean±standard deviation and median [interquartile range]) were used to describe the sample.

Qualitative data was analysed using deductive thematic analysis since there were preconceived themes expected to be found (i.e., impact of AECOPD, needs during AECOPD, thoughts about PR) which the research team wished to investigate while still maintaining flexibility to allow the generation of new themes. The six-step procedure of Braun and Clarke was followed. First, two researchers (AM and SA) familiarized themselves with the data by reading and rereading the transcriptions before the coding process began; independently organized units of text under each code, creating additional codes if new issues were identified; and organized the codes in themes and subthemes by combining the codes with similar or related ideas. Then, all researchers reviewed the data coded under each theme/subtheme; contributed for the appropriate naming and definition of the themes; and produced the report. The initial themes and subthemes found independently were compared between researchers (AM and SA) and, in case of disagreement, consensus was reached by discussion. All interviews were anonymised by assigning pseudonyms to each participant.

The analysis of the transcripts was conducted using the Web Qualitative Data Analysis (WebQDA) software. Representative quotes were included to support the interpretation of the identified themes and subthemes.

Rigor and Trustworthiness

The criteria of credibility, transferability, dependability and confirmability were used to ensure rigor and trustworthiness. Credibility was ensured through i) researcher triangulation, i.e., two researchers analysed each interview independently and then compared the analysis and agreed on the final themes/subthemes; ii) continuous discussion of the analysis and
interpretation of the data with all the research team; and iii) presentation of all the representative quotes in the results and supplementary material. Transferability was ensured by describing the characteristics of the researchers, participants, data collection and analysis in detail. Dependability and confirmability were ensured by triangulating the independent analysis of two researchers with different experiences and backgrounds, and discussing every step of the process with all the research team.

Results

Twelve people with AECOPD were approached to participate in this qualitative study and all agreed to participate. One was excluded after enrolment due to diagnosis of asthma-COPD overlap; therefore 11 people with AECOPD (9 male, 67±10 years, forced expiratory volume in one second 41±16% predicted, BMI 27±4kg/m²) were included in the analysis. Baseline characteristics of the study population are present in table 2.

Please insert Table 2 here.

Most participants were married (n=8; 73%), retired (n=9; 82%) and had completed primary school (n=7; 64%). The CAT scores revealed a high impact of the disease on most participants. Only 2 participants used LTOT and 1 non-invasive ventilation. About half of the sample (n=6; 55%) had previously participated in PR during the stable phase of the disease. The median interview time was 5min40sec (shortest: 3min; longest: 9min3sec).

Four main themes were identified: impact of AECOPD, dealing with AECOPD, main needs during AECOPD, and (un)certainty about PR. All themes and related subthemes are described in the following section and supported by quotations. Additional interview quotations can be found in the supplementary material.
Impact of AECOPD

All participants reported a negative impact of the AECOPD, which was described among six subthemes: symptoms, physiological changes, limitations in activities of daily living, social constrains, psychological and emotional challenges, and family disturbances (Figure 1).

Please insert Figure 1 here.

They all experienced the presence of several symptoms, namely shortness of breath, tiredness, lack of energy, cough, sputum, wheezing, pain and sleep disturbances, who often limited severely their daily life. Participants felt that some symptoms, such as shortness of breath and tiredness or cough and sputum, were related with each other and fluctuated along the day, being worse in the morning and at night, or when they had to make an effort.

“I feel really tired in the morning, I barely get up. As soon as I put my feet on the ground, I start dressing and I’m already tired. (...) My chest feels very tight. It seems that I have to make a huge effort to be able to breathe.” (Peter, 64)

People with AECOPD experienced some physiological changes, such as the loss of mental abilities and the lack of oxygen to help their brain and muscles to work.

“As I get older, I feel that the respiratory crises are getting worst, heavier, stronger. I feel increasingly less knowledgeable. I’m losing my abilities, both mental and physical. ” (Mary, 67)

Limitations in activities of daily living were also highly reported. Participants felt that the AECOPD limited their ability to perform their usual activities, both basic (e.g., walk, climb stairs, dressing, personal hygiene) “It is very hard to breathe, I can’t climb the stairs. (...)” (Mary, 67); instrumental (e.g., household activities, groceries, talk, transportation) “(...) I can’t even leave the house to catch the bus” (Mary, 67); and advanced (e.g., work, fishing, sing, go out with friends).
AECOPD also resulted in social constraints. Participants felt that they were not able to keep up with their peers, felt isolated, ashamed of having symptoms in front of others and indicated that their self-sufficiency was affected.

“I don’t want to expectorate in front of others, it is not pleasant. Neither for me, even less for the others.” (Ethan, 58)

The AECOPD impacted participants’ psychological and emotional well-being. People with AECOPD mentioned feeling down, scared, anxious, nervous, frustrated and with little desire to do things or even leave the house.

“Sometimes I get angry because I want to do something and I can’t... I feel frustrated.” (David, 72)

Lastly, David revealed that AECOPD impacted not only people with AECOPD but also their families.

“The sputum makes me feel desperate and then I bother my family, I know it.” (David, 72)

Dealing with AECOPD

Dealing with AECOPD was described among two subthemes: (not) depending on others, and planning and compensation strategies (Figure 2).

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Please insert Figure 2 here.

A dichotomy emerged regarding dependency on others, with participants reporting the need to rely on family to support them showering or climbing stairs, and others not wanting to be dependent. As James said:

“I shower alone. Sometimes my wife is at home, others she is not, because she has her own things to do, and often I only shower when she is back. Usually I shower alone, but I always calculate more or less how I am feeling so I don’t have any problems.” (James, 78)
Participants mentioned that during AECOPD they do fewer daily activities, perform everything more slowly and feel the need of having breaks. They also plan their routines depending on how they are feeling and try to compensate their symptoms by using breathing strategies and laying down barely moving. One participant reported using LTOT but not feeling dyspnoea relief.

“I reduce my daily activities. I also have to do them slower, but I reduce them. And I recover, and then I do another one. (…) Sometimes I think to myself, yoga breathing, with your belly, and it helps.” (Rose, 62)

Main needs during AECOPD

Four main needs during AECOPD emerged: to breathe better, to feel less tired, to get rid of sputum and to be able to walk (Figure 3).

Main needs of participants were focus on improving symptoms.

“I just wanted to get my chest better. The breathing. It is important, very important to me.” (Oliver, 63)

“I need to feel less tired. My problem is really the general tiredness.” (Peter, 64)

“My main need is the sputum, to get rid of this sputum. It is something that bothers me. If I don’t have sputum then I also don’t have the need to cough.” (David, 72)

Nevertheless, Michael also drawn attention to “Hmm… I would like to be able to walk like I used to walk.” (Michael, 58)

(Un)certainty about PR

People with AECOPD with previous PR contact shared their (un)certainty about PR through five subthemes: lack of knowledge, get better, exercises, design and timing, and trust in health
professionals (Figure 4). People naive to PR had more difficulties addressing this theme and three subthemes emerged: lack of knowledge, exercises, and design and timing.

Please insert Figure 4 here.

Lack of knowledge about PR was perceived by both, participants with previous PR contact and people naive to PR, who also felt the need of experiencing PR before sharing their thoughts “Oh that I don’t know, only at the end I will be able to tell you.” (Harry, 87)

Independently of their level of knowledge, people with AECOPD who had previous contact with PR believed it would be beneficial to them.

“I think it will be positive. Yes, I think I will get a bit better.” (Thomas, 56)

Conflicting ideas regarding exercises emerged, with one participant who was naive to PR feeling that both exercise training and breathing exercises could make her worse, while the others (with or without previous PR contact) mentioned exercises as something positive or even fundamental for their recovery.

“I think that, in the situation that I am in, due to the muscle mass or to what my body already asks for, the weakness, the oxygen, walking can help. I feel the walk training helps.” (Ethan, 58)

Several ideas regarding the design and timing of PR were reported. People with AECOPD with previous PR contact mentioned the importance of breathing techniques, individualization and education, namely about how to breathe. Opinions regarding exercise training were divided between less intense exercises with a shorter duration, or similar to a stability programme. One participant felt that it would be better to wait a few days to relief symptoms before starting PR. “Less intense exercises, without weights, or as long as it is not too heavy and it is not for too long, I don’t know. Less exercise time and lighter weights.” (Peter, 64) On the other hand, people naive to PR highlighted the relevance of exercises and education on
how to breathe and manage symptoms. “It would be important to learn how to manage symptoms.” (Oliver, 63)

Lastly, high levels of trust on health professionals were reported but only by those who had already experienced PR. “But you do everything (...) I know that you do everything to make me get better.” (John, 75)

**Discussion**

This study identified people’s experience during mild to moderate AECOPD, namely exacerbations’ impact and strategies to deal with it, main needs, and thoughts on PR during this period. To the authors’ best knowledge, this is the first study exploring the perceptions of people with mild to moderate AECOPD, conducted at the onset of an exacerbation.

AECOPD have a negative impact on people’s lives. Symptoms are the main concern at the onset of an AECOPD, but the variety of symptoms (e.g., cough, wheezing, lack of energy) reported by our participants was broader than previously described, emphasising the heterogeneity of exacerbations’ clinical presentation and the need for a comprehensive symptoms’ assessment. Limitations performing activities of daily living affect different dimensions than the ones reported by people with severe AECOPD, with impacts also on the advanced activities (e.g., work). Surprisingly, people with AECOPD noticed physiological changes, namely that they lacked oxygen in their brain with a negative impact on their mental abilities, which has not been reported in previous qualitative literature.

AECOPD further impacted people on a social, psychological, emotional and family level. Our study reinforces findings from existing literature, and adds that people with mild to moderate AECOPD also feel ashamed of having symptoms in front of others, little desire to do things, are not able to keep up with their peers and have their self-sufficiency affected.
This psychological burden leads to low functional performance and health-related quality of life, and is often neglected.

To deal with the AECOPD, people usually reduce their daily activities and/or perform them slower or after some breaks, planning and adjusting based on how they feel. Yet, some people just spend most of their day laying down or sitting on the couch barely moving. Since physical activity is the best predictor of mortality in this population, breaking this dyspnoea-inactivity vicious circle must be a goal of treatment strategies. Moreover, during AECOPD people demand additional support to perform their tasks, but there is a dichotomy between the ones who rely on their network for help and the ones who do not want to be dependent, highlighting the need to provide formal support to these people and their families.

In line with previous literature, the main needs reported during AECOPD were to breathe better, to feel less tired, to get rid of sputum and to be able to walk. Health professionals must therefore tailor interventions for this population to comply with these needs, namely by conducting pulmonary rehabilitation programmes that include not only exercise, education and psychosocial support, but also breathing techniques.

People with AECOPD naive to PR and with previous PR contact (stable disease) reported lack of knowledge on how PR should be delivered during AECOPD. This highlights the need to raise awareness to PR and educate the population about what it is and its benefits, and suggests that education on PR might enhance participation. Similarly to previous findings, in different severities of AECOPD and treatment settings, most participants considered important to have an individualized programme, including exercise training, breathing techniques and education. There was yet uncertainty regarding the timing and intensity of the programme.
In sum, we found that mild to moderate AECOPD have a negative impact on several aspects of people’s lives and share some similarities with reports from hospitalized people with severe AECOPD, emphasizing the importance of also providing proper interventions to manage mild to moderate AECOPD. The multitude of impacts and needs reported during the AECOPD require a comprehensive assessment, which allows the identification of the treatable traits possible to be addressed during a personalized PR programme. Previous literature has shown that PR is a safe intervention for the management of AECOPD that targets several of these treatable traits, namely, physical activity, exercise capacity, muscle weakness, dyspnoea and emotional burden. To address the complexity of people with AECOPD, an interdisciplinary team composed of physicians, physiotherapists, respiratory therapists, nurses, psychologists, behavioural specialists, occupation therapists, social workers and a care coordinator seems to be necessary.

Methodological considerations

This study has a number of strengths and limitations that need to be acknowledged. The performance of the interviews at the onset of the exacerbation prevented a potential memory bias related with the recall of the experience. Additionally, the most well-established guideline for reporting qualitative research (COREQ) was followed. Our main limitation was the short duration of the interviews, which might have affected the depth of the gathered information and was probably related with the acute phase they were experiencing, and the tiredness people felt. The sample included was small, but consistent with qualitative studies and a maximum variation sampling (e.g., gender, severity of the AECOPD, occupation, marital status) was used to ensure the representativeness of the population. Finally, as the interviews were conducted in Portuguese, the translation process might have influenced the
findings, particularly colloquial expressions or proverbs. However, we believe the main themes and conclusions are not affected by the translation process.

Conclusion

Mild to moderate AECOPD have a negative impact on people’s lives, even though no hospital admission is required. Symptoms were reported as the main feature, thus interventions focusing on symptomatic relief are needed. Further impacts were found on a physical, functional, psychological, emotional, social and family level, highlighting the importance of comprehensive assessments and interdisciplinary PR programmes. People with AECOPD considered PR beneficial but lacked knowledge about the intervention, highlighting the need to raise awareness to PR within this population. This study contributes with a foundation for the development of tailored and meaningful person-centred interventions during AECOPD.

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Author contributions: All authors contributed to conceptualization and/or design of the study. AM performed data collection. AM and SA performed the formal data analysis and all authors contributed to data interpretation. AM made the first draft of the manuscript, and all authors provided critical review of the manuscript and approved the final revision.

Declaration of interest: The authors have no conflict of interest to declare.
References


List of figures

Figure 1 – Thematic map for “Impact of AECOPD”. ADLs – activities of daily living;
AECOPD – acute exacerbation of chronic obstructive pulmonary disease.

Figure 2 – Thematic map for “Dealing with AECOPD”. AECOPD – acute exacerbation of chronic obstructive pulmonary disease.

Figure 3 – Thematic map for “Main needs during AECOPD”. AECOPD – acute exacerbation of chronic obstructive pulmonary disease.

Figure 4 – Thematic map for “(Un)certainty about PR”. PR – pulmonary rehabilitation.
Table 1 – Semi-structured interview guide applied to people with chronic obstructive pulmonary disease at the onset of their acute exacerbation.

<table>
<thead>
<tr>
<th>Interview questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Impact (positive or negative) the health problem has on you.</td>
</tr>
<tr>
<td>1.1. Which are the implications of the AECOPD on your daily life?</td>
</tr>
<tr>
<td>1.2. Which changes do you feel (e.g., signs, symptoms, quality of life)?</td>
</tr>
<tr>
<td>1.3. What are your main needs at the moment?</td>
</tr>
<tr>
<td>2. Impact (positive or negative) a PR programme could have on you.</td>
</tr>
<tr>
<td>2.1. Which are your goals and expectations about PR?</td>
</tr>
<tr>
<td>2.2. Which are the advantages and disadvantages of participating in PR?</td>
</tr>
<tr>
<td>3. Thoughts about how to conduct a PR programme during AECOPD.</td>
</tr>
</tbody>
</table>
Table 2 – Baseline characteristics of the study population (n=11).

<table>
<thead>
<tr>
<th></th>
<th>Age</th>
<th>Sex</th>
<th>FEV₁pp</th>
<th>AECOPD severity</th>
<th>No AECOPD previous year</th>
<th>Smoking status</th>
<th>CAT total score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mary</td>
<td>67</td>
<td>Female</td>
<td>55</td>
<td>Moderate</td>
<td>5</td>
<td>Never</td>
<td>29</td>
</tr>
<tr>
<td>John</td>
<td>75</td>
<td>Male</td>
<td>28</td>
<td>Moderate</td>
<td>0</td>
<td>Former</td>
<td>22</td>
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<tr>
<td>Peter</td>
<td>64</td>
<td>Male</td>
<td>32</td>
<td>Moderate</td>
<td>7</td>
<td>Former</td>
<td>30</td>
</tr>
<tr>
<td>James</td>
<td>78</td>
<td>Male</td>
<td>38</td>
<td>Mild</td>
<td>0</td>
<td>Former</td>
<td>24</td>
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<tr>
<td>Oliver</td>
<td>63</td>
<td>Male</td>
<td>51</td>
<td>Moderate</td>
<td>6</td>
<td>Former</td>
<td>18</td>
</tr>
<tr>
<td>Harry</td>
<td>87</td>
<td>Male</td>
<td>16</td>
<td>Moderate</td>
<td>1</td>
<td>Former</td>
<td>25</td>
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<tr>
<td>Rose</td>
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<td>Former</td>
<td>22</td>
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<tr>
<td>Ethan</td>
<td>58</td>
<td>Male</td>
<td>37</td>
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<td>1</td>
<td>Former</td>
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<tr>
<td>Thomas</td>
<td>56</td>
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<td>40</td>
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<tr>
<td>David</td>
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<td>1</td>
<td>Former</td>
<td>18</td>
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<tr>
<td>Michael</td>
<td>58</td>
<td>Male</td>
<td>27</td>
<td>Moderate</td>
<td>1</td>
<td>Former</td>
<td>19</td>
</tr>
</tbody>
</table>

Legend: AECOPD, acute exacerbation of chronic obstructive pulmonary disease; CAT; COPD assessment test; FEV₁pp, forced expiratory volume in 1 second percentage predicted.
Figure 1
Figure 2

Dealing with AECOPD

- (not) depending on others
- Planning and compensation strategies
Figure 3
Figure 4
Supplementary material: “Giving voice to people – experiences during mild to moderate acute exacerbations of COPD”

List of themes and subthemes

Impact of AECOPD

*Symptoms*
- Perceived symptoms
- Onset and daily variability
- Relation between symptoms

*Physiological changes*

*Limitations in activities of daily living*
- Basic activities of daily living
- Instrumental activities of daily living
- Advanced activities of daily living

*Social constrains*

*Psychological and emotional challenges*

*Family disturbances*

Dealing with AECOPD

*(not) depending on others*

*Planning and compensation strategies*

Main needs during AECOPD

*Breathe better*
*Breathe better*
*Feel less tired*
*Feel less tired*
*Get rid of sputum*
*Get rid of sputum*
*Be able to walk*
*Be able to walk*

(Un)certainty about PR

*Lack of knowledge*
*Lack of knowledge*
*Get better*
*Get better*
*Exercises*
*Exercises*
*Design and timing*
*Design and timing*
*Trust in health professionals*
*Trust in health professionals*
List of quotations supporting each theme/subtheme

Impact of AECOPD

Symptoms

Perceived symptoms

“So, I walk, yes, I know what I do and what I say, but I don’t have strength, I suffer a lot with lack of energy.” (Mary, 67)

“It is very difficult to breathe.” (Mary, 67)

“I don’t have strength and energy.” (Mary, 67)

“It is hard to breathe…” (Mary, 67)

“It is the tiredness, the tiredness. The breathing, the shortness of breath.” (John, 75)

“Now I have more sputum and it gets stuck if I don’t take the medicine.” (John, 75)

“I feel really tired in the morning, I barely get up. As soon as I put my feet on the ground, I start dressing and I’m already tired.” (Peter, 64)

“Now I have cough and sputum.” (Peter, 64)

“My chest feels very tight. It seems that I have to make a huge effort to be able to breathe. I’m making a lot of effort, I’m really making a really big effort to be able to breathe.” (Peter, 64)

“I also have some wheezing in the morning.” (Peter, 64)

“The shortness of breath. A bit of lack of energy also. Because usually, when I have acute exacerbations, I have shortness of breath and I also get way more tired than the usual.” (James, 78)

“I have sputum and cough to go along with it.” (James, 78)

“I feel tired.” (James, 78)

“Sometimes I have cough. I’ve already been in the doctor because of it.” (Oliver, 63)

“I feel that my chest is heavy and wheezing also.” (Oliver, 63)

“The shortness of breath, the shortness of breath, it is what I notice, my biggest difficulty. It is the shortness of breath.” (Harry, 87)

“I take a deep breath but there is something that holds it, it seems that it is stuck inside.” (Harry, 87)

“I get exhausted, the difficulty is to breathe and physical. I get exhausted, what I call exhaustion.” (Rose, 62)

“It was the pain. It was the pain, the shortness of breath also, but mainly the pain.” (Ethan, 58)

“I feel that I have sandpaper or a claw here in the bronchial area that scratches when I breath, it seems like the air is carrying sand together. And pain, and itchy throat and a bit of cough, but a dry cough. Now taking the medicine the sputum is already coming out, little by little, a little greenish.” (Ethan, 58)

“When I talk for a bit, I start coughing like I am doing now.” (Ethan, 58)
“When I breathe it feels like sandpaper inside.” (Ethan, 58)

“Mainly sputum is something that makes me very distressed. It bothers me a lot. And the more I cough, the more difficult it becomes to get out. But when it gets out it is like a fried egg. The sputum is much more quantity and thicker too.” (Thomas, 56)

“When I start to cough a lot, I feel very tired.” (Thomas, 56)

“The wheezing is the number one. It seems like a grill frying chips.” (Thomas, 56)

“The sputum is what has really created more problems for me, because it is true that afterwards I become more desperate.” (David, 72)

“Sometimes I avoid to expectorate because I know that afterwards I will get even more tired.” (David, 72)

“As at night I have more cough and sputum, then it is more difficult to fall asleep. But if I don’t expectorate then I can’t sleep.” (David, 72)

“After expectorating several times, if I expectorate everything I can, then I’m able to sleep... I don’t say for hours and hours, but for some good two to three hours.” (David, 72)

“If I don’t have the need to expectorate, then I’m completely well without a problem. When I do have the need to expectorate, then it is when it comes the so-called seizure and everything comes.” (David, 72)

“I feel short of breath.” (Michael, 58)

“It is the short of breath and the tiredness.” (Michael, 58)

Onset and daily variability

“The weather also has a lot of influence.” (John, 75)

“I feel really tired in the morning, I barely get up. As soon as I put my feet on the ground, I start dressing and I’m already tired.” (Peter, 64)

“I also have a bit of wheezing in the morning, at least as soon as I wake up and at night I start wheezing. It is in the morning and at night. During the day I don’t have barely anything. At night and in the morning I have more wheezing and also more sputum. And when I have more wheezing then I also become much more tired.” (Peter, 64)

“During the day the tiredness becomes better. Around 6 or 7 pm it is when it starts to get worse again.” (Peter, 64)

“Sometimes it’s a bit difficult to get the sputum out, other times it comes out better.” (Peter, 64)

“The sputum and cough occur more at night.” (James, 78)

“At night usually I am not tired nor short of breath. Neither in the morning. Usually walking, doing things and walking it is when I start to feel tired.” (James, 78)
“The steam, the humidity of the hot air. Too much sun also. And when there is a lot of rain, I find myself desperate.” (Ethan, 58)

“When I talk for a while, I cough just like I am doing now.” (Ethan, 58)

“It is difficult to breath mainly when I am making efforts.” (Thomas, 56)

“When I am making a little bit of effort, it is when I feel I start wheezing more. Besides that, when I am sitting or lying, if I am straight like this I feel a lot of wheezing, if I raised the headboard then I feel less wheezing.” (Thomas, 56)

“I have moments that I feel more relieved [regarding cough and sputum]. And I have other moments that are worst, mainly at night when I go to bed, maybe because of the heat of the bed, I don’t know, I feel more affected. In the morning when I get up I also feel it a bit, but then during the day it gets better.” (David, 72)

Relation between symptoms

“It is the general tiredness. And then I get very distressed, I get this tightness.” (Peter, 64)

“When the wheezing starts, I become much more tired.” (Peter, 64)

“When the wheezing starts, I hear this cricket here, and I already know that I am much more tired.” (Peter, 64)

“The problem is that the sputum might be also contributing to this tiredness.” (Peter, 64)

“I believe that by relieving the sputum then it would also improve the cough.” (Peter, 64)

“Because usually when I have acute exacerbations, I have shortness of breath and I also get way more tired than the usual.” (James, 78)

“And then when something doesn’t go well, I get nervous, and it is worst. Then, it is even worse.” (James, 78)

“Because if I was able to breath better the tiredness wouldn’t be so much. I believe it wouldn’t.” (James, 78)

“If I have to hurry up I immediately become distressed. And if I get a bit nervous then it is even worse.” (Harry, 87)

“Shortness of breath and tiredness. Both things. One is not without the other.” (Rose, 62)

“I become anxious. And I find it more difficult to breath because I am anxious.” (Rose, 62)

“The tiredness and shortness of breath, they are connected.” (Ethan, 58)

“And the more I cough, the more difficult it becomes to get the sputum out.” (Thomas, 56)

“When I cough, when I start coughing a lot I feel really tired.” (Thomas, 56)

“Sometimes I avoid to expectorate because I know that afterwards I will get even more tired.” (David, 72)
“The cough, you know, one thing is connected with the other, the cough pulls the sputum and sometimes the sputum is a little more difficult and pulls the cough.” (David, 72)

“As at night I have more cough and sputum, then it is more difficult to fall asleep. But if I don’t expectorate then I can’t sleep.” (David, 72)

“After expectorating several times, if I expectorate everything I can, then I’m able to sleep...” (David, 72)

“If I don’t have sputum then I also don’t have the need to cough.” (David, 72)

Physiological changes

“I feel that I’m lacking oxygen. And then my brain starts working, and there is something missing when I want to walk, when I want to breath and I can’t, and I feel that I lack something to be able to put inside what I may not be able to get normally, to cheer me up.” (Mary, 67)

“As I get older, I feel that the respiratory crises are getting worst, heavier, stronger. I feel increasingly less knowledgeable. I’m loosing my abilities, both mental and physical.” (Mary, 67)

“The air, the peripheral oxygen saturation doesn’t decrease much.” (Peter, 64)

“My problem is breathing and also physical.” (Rose, 62)

“It is like if there was no oxygen in my muscles and then I feel my legs really heavy.” (Ethan, 58)

Limitations in activities of daily living

“I want to do something and I can’t. I am going to do it and I have to stop.” (Mary, 67)

“I have to stop. What I used to do in one or two minutes now it may take me almost half an hour.” (Mary, 67)

“There are things that I have to do more slowly.” (John, 75)

“It changes everything because I feel very dizzy.” (Peter, 64)

“Before I used to do almost everything, I used to do everything more or less as everyone. Now I can’t.” (Peter, 64)

“Before I wasn’t able to do everything but I was able to do much more than now.” (James, 78)

“Anything that I have to do at home, I have to do it slower than before.” (James, 78)

“It affects my ability to walk. When I want to do something, I can’t.” (Harry, 87)

“I can’t. I want to do something and I become stuck, I feel there is something arrest inside, I don’t know.” (Harry, 87)

“It affects my quality of life because I am a very active person.” (Rose, 62)

“For me it is a bit bad because it doesn’t let me do what I want.” (Thomas, 56)

“The impact is negative, without a doubt.” (David, 72)
“Sometimes I have to stop what I am doing to expectorate, I have to go to the bathroom or to the garbage dump.” (David, 72)

Basic activities of daily living

“It is very hard to breathe, I can’t climb the stairs.” (Mary, 67)

“Even to go to the bathroom is hard for me at the moment. So, I make a really big effort to be able to do it.” (Mary, 67)

“As soon as I put my feet on the ground, I start dressing and I’m already tired. Even getting dressed. Taking a shower is another problem. A few days ago, I tried to take a shower when there was no one at home... I am not able to do it anymore, only when my wife or my daughter are at home, because I am scared of taking a shower alone. I was taking a bathtub and found myself really in distress.” (Peter, 64)

“I have to take a shower really slowly.” (Peter, 64)

“Going down the stairs in the building there is no problem, my problem is to climb the stairs, because I know that when I go down then I have to climb them. Sometimes I stay downstairs waiting for my wife to arrive so that I can come up with her.” (Peter, 64)

“It makes it difficult to walk.” (Harry, 87)

“I need to walk the usual, what I feel it is the usual, and the acute exacerbation makes it difficult.” (Rose, 62)

“It makes it difficult to, for example, I put on some shoes and I am already tired. Walking a bit, after 10, 15, 20 meters I have to stop or at least slow down.” (Ethan, 58)

“I feel that I am not able to walk like other people.” (Michael, 58)

Instrumental activities of daily living

“I can’t do my regular activities, not even making the bed. Something as simple as making the bed at this moment I can’t.” (Mary, 67)

“I can’t even leave the house to catch the bus.” (Mary, 67)

“While climbing stairs I can’t carry anything with me. Before I was able to carry some groceries, now I cannot carry anything at all.” (Peter, 64)

“I feel short of breath while talking.” (Ethan, 58)

“I would like to be able to carry some weights, and also to go grocery shopping and come back carrying the bags, but I cannot do it anymore because it is difficult.” (Thomas, 56)

Advanced activities of daily living
“Now I can’t go fishing. I used to entertain myself by going fishing and I spent the time better, but now I can’t.” (Peter, 64)

“I had to unscheduled all my work, from morning to night, it was the day I work the most and I had to unscheduled everything. Also because I was going to be sabotaging my work, I wouldn’t be able to do it properly. It also reduces my productivity and affects my self-sufficiency.” (Ethan, 58)

“There is one thing that I’ve noticed that it is difficult for me to sing.” (Ethan, 58)

“Sometimes I can’t go with my friends here and there. I can no longer keep up with them.” (Michael, 58)

“I want to have fun, to be able to go to everything, and I can’t go...” (Michael, 58)

**Social constrains**

“It affects my self-sufficiency. And isolation, of course, isolation.” (Ethan, 58)

“I don’t want to expectorate in front of others, it is not pleasant. Neither for me, even less for the others.” (Ethan, 58)

“If I need to expectorate, I am careful to expectorate to a proper local like a tissue.” (David, 72)

“Sometimes I can’t go with my friends here and there. I can no longer keep up with them.” (Michael, 58)

“I want to have fun, to be able to go to everything, and I can’t go...” (Michael, 58)

“I could go somewhere but if I have cough I don’t go inside, I don’t go there. Sometimes because of other people.” (Michael, 58)

**Psychological and emotional challenges**

“I feel really down. And then I get nervous because I want to do something, and I can’t. I am going to do it and I have to stop.” (Mary, 67)

“So I make a really big effort to be able to do it.” (Mary, 67)

“I was always a very active woman but with these respiratory crises I am getting worse and worse. I feel I am going down.” (Mary, 67)

“I don’t even want to go outside anymore. I just don’t want to. I no longer want to do anything; I don’t feel like leaving the house anymore.” (Peter, 64)

“A few days ago, I tried to have a shower when there was no one at home... I am not able to do it anymore, only when my wife or my daughter are at home, because I am scared of taking a shower alone. I am scared of getting short of breath and then there is no one there to help me.” (Peter, 64)
“A few days ago I was having a bathtub and I had to go to the living room in distress with a feeling like... maybe it was panic, I don’t know. I get anxious. I was having a bathtub and found myself in distress, probably it was fear, I don’t know.” (Peter, 64)

“In the morning I walk around inside the house, from side to side, I feel like a prisoner, everything upsets me already.” (Peter, 64)

“Now I don’t even try to go fishing because I already think that something will go wrong, so I don’t even go, I don’t even pick the fishing rod.” (Peter, 64)

“I feel little desire to do certain things.” (James, 78)

“When something doesn’t go well, I get nervous and then it is even worse.” (James, 78)

“It is hard for me to cope with the difficulty to breath. I mean, I don’t know how to handle it.” (Rose, 62)

“I become anxious. And I find it more difficult to breath because I am anxious.” (Rose, 62)

“There is a feeling of frailty and disability.” (Ethan, 58)

“And it was the state that I became due to pain, it sent me really down and I got discouraged.” (Ethan, 58)

“I don’t feel like going out, and then inwardly I want to unscheduled things. And isolation, of course, isolation.” (Ethan, 58)

“Besides being bothering others, it also bothers me because I feel I had no need to do it but I have to, I have to expectorate.” (David, 72)

“Sometimes I get angry because I want to do something and I can’t... I feel frustrated.” (David, 72)

“I could go somewhere but if I have cough I don’t go inside, I don’t go there. Sometimes because of other people.” (Michael, 58)

**Family disturbances**

“The sputum makes me feel desperate and then I bother my family, I know it.” (David, 72)

“Besides being bothering others, it also bothers me because...” (David, 72)

“I get a bit angry because I want to do something and I can’t, and then maybe I create a bit of a bad environment at home.” (David, 72)
Dealing with AECOPD

(not) depending on others

“A few days ago, I tried to have a shower when there was no one at home… I am not able to do it anymore, only when my wife or my daughter are at home, because I am scared of taking a shower alone.” (Peter, 64)

“Going down the stairs in the building there is no problem, my problem is to climb the stairs, because I know that when I go down then I have to come up. Sometimes I stay downstairs waiting for my wife to arrive so that I can come up with her.” (Peter, 64)

“I shower alone. Sometimes my wife is at home, others she is not, because she has her own things to do, and often I only shower when she is back. Usually I shower alone, but I always calculate more or less how I am feeling so I don’t have any problems.” (James, 78)

Planning and compensation strategies

“It is very hard to breathe, I can’t climb the stairs, I have to climb them step by step. One step stop, another one stop, always like this, for someone who lives in the third floor.” (Mary, 67)

“And what helps me is the car, because if it wasn’t the car…” (Mary, 67)

“I have to stop. What I used to do in one or two minutes now it may take me almost half an hour.” (Mary, 67)

“The way I feel better is lying down, barely moving.” (Mary, 67)

“There are things that I have to do more slowly.” (John, 75)

“I have to take a shower really slowly.” (Peter, 64)

“I leave the house but I can only do it around 10:30 or 11am. Before I would left the house immediately, at 9am or even earlier.” (Peter, 64)

“I have to climb the stairs slowly and split them in three or four parts. And I can’t carry anything with me.” (Peter, 64)

“I’m making a lot of effort, I’m really making a really big effort to be able to breath. But if I use the oxygen, it is the same. I don’t feel differences, I’m still making an effort, making a really big effort to be able to breath.” (Peter, 64)

“Anything that I have to do at home, I have to do it slower than before.” (James, 78)

“I shower alone. Sometimes my wife is at home, others she is not, because she has her own things to do, and often I only shower when she is back. Usually I shower alone, but I always calculate more or less how I am feeling so I don’t have any problems.” (James, 78)

“I reduce my daily activities. I also have to do them slower, but I reduce them. And I recover, and then I do another one.” (Rose, 62)
“Sometimes I think to myself, yoga breathing, with your belly, and it helps.” (Rose, 62)
“Walking a bit, after 10, 15, 20 meters I have to stop or at least slow down.” (Ethan, 58)
“When I talk for a bit, I start coughing like I am doing now. It means that now I’ll have to remain silent for a while to rest.” (Ethan, 58)

Main needs during AECOPD

**Breathe better**

“I need to improve my respiration.” (Mary, 67)
“What I feel I need is the air. Because if I have air it gives me (at least I think) more agility, which is what I am lacking at this moment.” (Mary, 67)
“I need to breathe better and to feel less tired.” (John, 75)
“I need to breathe better. Because if I breathed better the tiredness wouldn’t be so much. At least I suppose it wouldn’t.” (James, 78)
“I just wanted to get my chest better. The breathing. It is important, very important to me.” (Oliver, 63)
“I need to breath better and to feel less tired.” (Oliver, 63)
“I would like to improve this part of getting air inside... the air, the air.” (Harry, 87)
“I would like to improve my respiration. To open my chest... sometimes I feel it is heavy, tight, I don’t know how to explain it.” (Rose, 62)
“I need to feel less tired and to breathe better, they are connected.” (Ethan, 58)
“I need to have more ability to breath.” (Ethan, 58)
“I need the breathing to get back to normal. Normal is difficult, but at least improve the respiratory part. Especially when I’m making efforts. That’s when I would like you to help me more, so I can be more comfortable.” (Thomas, 56)

**Feel less tired**

“I need to breathe better and to feel less tired.” (John, 75)
“I need to feel less tired. My problem is really the general tiredness.” (Peter, 64)
“Heck, if I wasn’t always tired I would get better, feel better.” (Peter, 64)
“I need to feel less tired.” (Peter, 64)
“I need to breathe better and to feel less tired.” (Oliver, 63)
“I need to feel less tired and to breathe better, they are connected.” (Ethan, 58)
Get rid of sputum

“I believe it is important to relief the sputum.” (James, 78)

“My main need is the sputum, to get rid of this sputum. It is something that bothers me. If I don’t have sputum then I also don’t have the need to cough.” (David, 72)

“When I do have the need to expectorate, then it is when it comes the so-called seizure and everything comes. That is my main problem.” (David, 72)

Be able to walk

“Hmm... I would like to be able to walk like I used to walk. I would get up at 5 or 6 am and just go.” (Michael, 58)

“I want to be able to walk.” (Michael, 58)

“I want to be able to walk, to be able to walk at my own will.” (Michael, 58)

(Un)certainty about PR

Lack of knowledge

“I have no idea, one session at a time.” (Mary, 67)

“I don’t know, I haven’t seen it yet.” (John, 75)

“Oh that I don’t know, only at the end I will be able to tell you.” (Harry, 87)

“First I had to be aware of the plan that you have, to know what favours me.” (Ethan, 58)

“Only the health professionals will be able to know.” (Thomas, 56)

Get better

“I think, well I want to get better.” (John, 75)

“My idea is to get better.” (John, 75)

“I think I will get better. Possibly in everything, but at least the tiredness.” (Peter, 64)

“I think I will get better, yes, yes, yes. It will get better.” (James, 78)

“I think it will be positive. Yes, I think I will get a bit better. My expectations are always for everything to happen better. To always get better, may it be better for me.” (Thomas, 56)

“My expectations are always to get better.” (Thomas, 56)

Exercises

“I think the exercises could make me get even worse.” (Mary, 67)

“Hmm, the breathing exercises in this critical phase help me even less.” (Mary, 67)
“The physical exercises improve, improve... If it doesn’t improve it also doesn’t get worse.” (John, 75)
“For example the exercise with the chair, I like to do it. I get tired immediately. It helps, it helps.” (Oliver, 63)
“I like to do the exercises at home. Later I am already going to do this exercise by myself.” (Oliver, 63)
“I think that, in the situation that I am in, due to the muscle mass or to what my body already asks for, the weakness, the oxygen, walking can help. I feel the walk training helps.” (Ethan, 58)
“I am sure. To exercise is fundamental. Because... the muscles ask for more.” (Ethan, 58)

Design and timing

“There are different exercises, some more intense, others less intense.” (John, 75)
“You learn a little of everything.” (John, 75)
“It would be important to learn how to breath.” (John, 75)
“Anything that involves a lot of effort I can’t, at this moment I can’t do big efforts. Less intense exercises, without weights, or as long as it is not too heavy and it is not for too long, I don’t know. Less exercise time and lighter weights.” (Peter, 64)
“The breathing techniques would help.” (Peter, 64)
“I think it can be similar to the stability pulmonary rehabilitation programme.” (James, 78)
“I do the same exercises, even if they feel a bit more difficult.” (James, 78)
“I think I should wait two or three days. (...) In two or three days my breathing might be better, I believe.” (James, 78)
“The breathing techniques would help.” (James, 78)
“I think the education and psychosocial support sessions could be about the same themes, from my point of view I think it is everything normal.” (James, 78)
“It would be important to learn how to manage symptoms.” (Oliver, 63)
“Hmm... Rehabilitation could be with exercises that I could learn that would open my chest and help me breathe better. Maybe there is a way I could breathe better, no?” (Rose, 62)
“First I have to be aware of the plan that you have, to know what favours me, and then understand what fits me, in my individual case.” (Ethan, 58)

Trust in health professionals

“But you do everything (...) I know that you do everything to make me get better.” (John, 75)
“Only the health professionals will be able to know.” (Thomas, 56)
“I trust in people. Especially in the health professionals.” (Thomas, 56)