Chronic Obstructive Pulmonary Diseases:

Journal of the COPD Foundation®



Original Research

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

Ana Machado, PT, MSc1,2,3,4 Sara Almeida, GT, MSc, PhD1,5 Chris Burtin, PT, MSc, PhD3,4 Alda Marques, PT, MSc, PhD1,5

Abstract

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

Methods: Short, semi-structured interviews were conducted with people with mild to moderate AECOPDs treated on an outpatient basis, within 48 hours of the diagnosis. Interviews were audio recorded, transcribed, and analyzed by deductive thematic analysis using the Web Qualitative Data Analysis software.

Results: Eleven people with AECOPDs (9 male, 67±10 years, forced expiratory volume in 1 second 41±16% predicted) participated. Four themes and 17 subthemes were identified: impact of an AECOPD (symptoms, physiological changes, limitations in activities of daily living, social constraints, psychological and emotional challenges, family disturbances); dealing with an AECOPD, ([not] depending on others, planning and compensation strategies); main needs during an AECOPD (breathe better, feel less tired, get rid of sputum, be able to walk); and (un)certainty about PR (lack of knowledge, getting better, exercises, design and timing, trust in health professionals).

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

Abbreviations: acute exacerbation of chronic obstructive pulmonary disease, **AECOPD**; pulmonary rehabilitation, **PR**; randomized controlled trial, **RCT**; Consolidated Criteria for Reporting Qualitative Research, **COREQ**; Global initiative for chronic Obstructive Lung Disease, **GOLD**; body mass index, **BMI**; long-term oxygen therapy, **LTOT**; COPD Assessment Test, **CAT**; Web Qualitative Data Analysis, **WebQDA**; forced expiratory volume in 1 second, **FEV**₁; activities of daily living, **ADLs**

Funding Support: This work was funded by Fundação para a Ciência e a Tecnologia under the PhD grant SFRH/BD/147200/2019. This work was also supported by the project "CENTR(AR): pulmões em andamento" via Programa de Parcerias para o Impacto, Portugal Inovação Social through Programa Operacional Inclusão Social e Emprego (POISE-03-4639-FSE-000597), by Fundo Social Europeu through Programa Operacional Regional Centro, and by Programa Operacional Competitividade e Internacionalização (COMPETE 2020 - POCI-01-0145-FEDER-007628; UIDB/04501/2020).

Date of Acceptance: May 4, 2022 | Published Online Date: May 6, 2022

Citation: Machado A, Almeida S, Burtin C, Marques A. Giving voice to people – experiences during mild to moderate acute exacerbations of COPD. *Chronic Obstr Pulm Dis.* 2022;9(3):336-348. doi: https://doi.org/10.15326/jcopdf.2022.0283

- 1. Institute of Biomedicine, University of Aveiro, Aveiro, Portugal
- Department of Medical Sciences, University of Aveiro, Aveiro, Portugal
- 3. Rehabilitation Research Center, Faculty of Rehabilitation Sciences, Hasselt University, Diepenbeek, Belgium
- 4. Biomedical Research Institute, Hasselt University, Diepenbeek, Belgium
- 5. Respiratory Research and Rehabilitation Laboratory, School of Health Sciences, University of Aveiro, Aveiro, Portugal

Address correspondence to:

Alda Marques, PT, MSc, PhD
Respiratory Research and Rehabilitation Laboratory
School of Health Sciences and Institute of Biomedicine
University of Aveiro, Agras do Crasto
Campus Universitário de Santiago
Edifício 30, 3810-193
Aveiro, Portugal
Email: amarques@ua.pt

Email: amarques@ua.pt Phone: 00 +351 234372462

Keywords:

exacerbations; COPD; pulmonary rehabilitation; person-centered; qualitative research

This article has an online data supplement.

Note: Part of this work was presented at the European Respiratory Society International Congress 2021 as an e-poster.

Introduction

Acute exacerbations of chronic obstructive pulmonary disease (AECOPDs) are defined as an acute worsening of respiratory symptoms that result in additional therapy.^{1,2} A recent proposal on an updated definition of an AECOPD states that these events are characterized by dyspnea and/or cough and sputum that worsens over a period of 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 (≈110,000 deaths/year), accounting for 50%-75% of all diseaserelated costs. 1,6-8 AECOPDs lead to a significant decline in individuals' lung function, exercise performance, and quality of life, and increase their susceptibility to subsequent AECOPDs. 1,6,8 The goals of treatment for AECOPDs are, therefore, to minimize their impact and prevent the development of subsequent events.¹

Current management of AECOPDs (e.g., pharmacological treatment) is only partly effective, and thus, research on this topic is a well-established priority. AECOPDs 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 AECOPDs as it appears that physicians

have been underestimating it, which may contribute to undertreatment. 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 4 explored the impacts of moderate AECOPDs from individuals' perspectives, but its retrospective design (i.e., people recalling the exacerbation experience) may have induced an important recall bias. 18,19 Prospective studies on individuals with mild to moderate AECOPDs are 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.¹ Evidence for the use of PR in the management of people during and after AECOPDs has been increasing recently.²³⁻²⁵ Nevertheless, quantitative studies have been mainly conducted in hospitalized individuals with AECOPDs, when more than 80% of all AECOPDs are managed on an outpatient basis (i.e., mild to moderate exacerbations)^{1,26}; and qualitative studies have mainly focused on the period following the AECOPD.^{27,28} Moreover, people with AECOPDs differ from those with stable disease, and currently there are no guidelines on how to conduct PR tailored to individuals' needs and specificities during an AECOPD.^{23,25,27,29}

Listening to the perceptions of individuals during AECOPDs, 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 that is tailored to their preferences.^{27,30} This person-centered approach could improve the management of AECOPDs and help ensure PR's effectiveness.²⁷ Thus, this qualitative study aimed to understand individuals' experiences (i.e., needs, impact, perceptions) during mild to moderate AECOPDs. We also explored their thoughts on PR during an AECOPD as a secondary aim.

Methods

This qualitative study was nested in a randomized controlled trial (RCT)³¹ evaluating the effectiveness of a PR program during AECOPDs treated on an outpatient basis. The Consolidated Criteria for Reporting Qualitative Research (COREQ)³² was followed. The ethic committees of the Health Sciences Research Unit: Nursing (P618-10/2019), Unidade Local de Saúde de Matosinhos

(73/CE/JAS), Centro Hospitalar do Baixo Vouga (15.23-2020) and Administração Regional de Saúde do Centro (85/2018) 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., AECOPDs) through participants' experiences.³³

Participants

A convenience sample was used. Individuals with AECOPDs were consecutively recruited from participants of the RCT between January 2019 and February 2020. Individuals were eligible for the RCT if they were: (1) diagnosed with an AECOPD according to the Global initiative for chronic Obstructive Lung Disease (GOLD)¹ criteria, i.e., presenting an acute worsening of respiratory symptoms that resulted in additional therapy (e.g., antibiotics, corticosteroids, bronchodilators); (2) could be included within 48 hours of the diagnosis; (3) managed on an outpatient basis; and (4) able to provide informed consent. Exclusion criteria included: (1) unstable cardiovascular disease, (2) significant musculoskeletal or neuromuscular impairment that precluded the adequate performance of the tests or participation in PR (e.g., amputation, Parkinson's disease), (3) signs of cognitive impairment, (4) current neoplasia or immunological disease, and (5) any therapeutic intervention in addition to standard of care (i.e., pharmacological treatment). All diagnoses of AECOPD were performed by clinicians at the hospitals and primary care centers involved in the study. At the time of the first coronavirus disease 2019 (COVID-19) lockdown, recruitment stopped since data from individuals with AECOPDs during the pandemic could not be compared with previous data. The pandemic impacted the number and severity of AECOPDs and resulted in significant behavioral and social changes.³⁴

Data Collection

Data collection was conducted at the Respiratory Research and Rehabilitation Laboratory or at participants' own homes, according to their preference, within 48 hours 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 characterize the sample. Severity of the AECOPD was classified according to 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 population¹ and the one presenting more robust measurement properties during an AECOPD.³⁵ 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.³⁶ Then, short, semistructured, face-to-face interviews were conducted. Semi-structured interviews with open-ended questions were chosen as this approach allows us to understand participants' experiences and the emergence of new topics that are important to them and have not been previously thought as relevant by the research team. 37,38 A semi-structured interview guide (Table 1) informed by the literature, the previous experience of the team, and an experienced qualitative researcher, was used to ensure that the topics under investigation were covered in a consistent manner while allowing for flexibility. The interview guide integrated questions about participants' experiences during an AECOPD and their thoughts on PR. The interviews were audio recorded (Olympus digital voice recorder WS-750m) and transcribed verbatim, with participants' names anonymized.

AM, a physiotherapist (PhD student), contacted the participants for the study, led the qualitative interviews, transcribed them, and was involved in the analysis. SA, a gerontologist (PhD), reviewed the transcriptions and was involved in the analysis. CB, a physiotherapist

Table 1. Semi-Structured Interview Guide Used with Individuals with COPD at the Onset of Their Acute Exacerbation

Interview Questions

- 1. Impact (positive or negative) the health problem has on you.
 - 1.1 What are the implications of the AECOPD on your daily life?
 - 1.2 Which changes do you feel (e.g., signs, symptoms, quality of life)?
 - 1.3 What are your main needs at the moment?
- 2. Impact (positive or negative) a PR program could have on you.
 - 2.1 What are your goals and expectations about PR?
 - 2.2 What are the advantages and disadvantages of participating in PR?
- 3. Thoughts about how to conduct a PR program during AECOPD.

COPD=chronic obstructive pulmonary disease; AECOPD=acute exacerbation of COPD; PR=pulmonary rehabilitation

(senior researcher), and ASM, a physiotherapist (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 analyzed using deductive thematic analysis since there were preconceived themes expected to be found (i.e., impact of an AECOPD, needs during an AECOPD, and thoughts about PR) which the research team wished to investigate while still maintaining flexibility to allow for the generation of new themes.³⁹ The 6-step procedure of Braun and Clarke was followed.³⁹ First, 2 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 to 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 anonymized 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. 40 Credibility was ensured through: (1) researcher triangulation, i.e., 2 researchers analyzed each interview independently and then compared the analysis and agreed on the final themes/subthemes, (2) continuous discussion of the analysis and interpretation of the data with the entire research team, and (3) 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 2 researchers with different experiences and backgrounds and discussing every step of the process with the entire research team.

Results

Twelve individuals with AECOPDs were approached to participate in this qualitative study and all agreed to participate. One was excluded after enrollment due to diagnosis of asthma-COPD overlap. Therefore, 11 individuals with AECOPD (9 male, 67±10 years, forced expiratory volume in 1second [FEV₁] 41±16%predicted, BMI 27±4kg/m²) were included in the analysis. Baseline characteristics of the study population are present in Table 2.

Most participants were married (n=8; 73%), retired (n=9; 82%,), and had completed primary school (n=7; 64%). The CAT scores revealed the disease had a high impact on most participants. Only 2 participants used LTOT and 1 used non-invasive ventilation. About half of the sample (n=6; 55%) had previously participated in PR during the stable phase of their disease. The median interview time was 5 min, 40sec (shortest: 3min; longest: 9min, 3sec).

Four main themes were identified: impact of the AECOPD, dealing with an AECOPD, main needs during an 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 online supplement.

Impact of Acute Exacerbations of COPD

All participants reported a negative impact of the AECOPD, which was described with 6 subthemes: symptoms, physiological changes, limitations in activities of daily living, social constraints, psychological and emotional challenges, and family disturbances (Figure 1).

They all experienced the presence of several symptoms, namely shortness of breath, tiredness, lack of energy, cough, sputum, wheezing, pain, and sleep disturbances, which often severely limited their daily life. Participants felt that some symptoms, such as shortness of breath and tiredness or cough and sputum, were

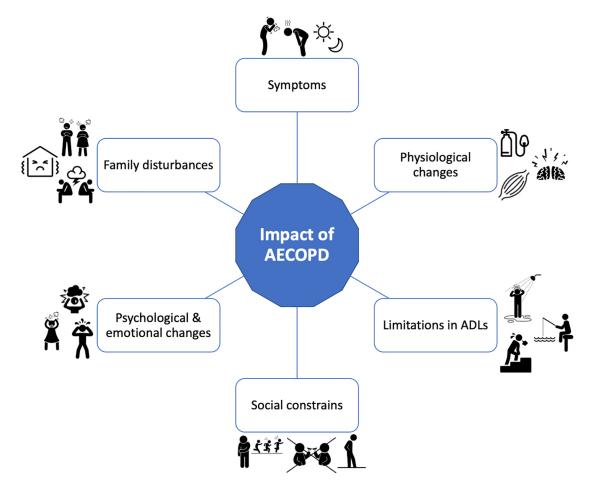
Table 2. Baseline Characteristics of the Study Population^a

	Age	Sex	FEV ₁ %pred	AECOPD Severity	No AECOPD previous year	Smoking Status	CAT Total Score
Mary	67	Female	55	Moderate	5	Never	29
John	75	Male	28	Moderate	0	Former	22
Peter	64	Male	32	Moderate	7	Former	30
James	78	Male	38	Mild	0	Former	24
Oliver	63	Male	51	Moderate	6	Former	18
Harry	87	Male	16	Moderate	1	Former	25
Rose	62	Female	59	Moderate	2	Former	22
Ethan	58	Male	37	Moderate	1	Former	23
Thomas	56	Male	40	Moderate	1	Former	29
David	72	Male	69	Moderate	1	Former	18
Michael	58	Male	27	Moderate	1	Former	19

^an=11

FEV1% pred=forced expiratory volume in 1 second percentage predicted; AECOPD=acute exacerbation of chronic obstructive pulmonary disease; CAT=COPD Assessment Test

Figure 1. Thematic Map for: Impact of an Acute Exacerbation of COPD



AECOPD-acute exacerbation of chronic obstructive pulmonary disease; ADLs-activities of daily living;

related to each other and fluctuated through the day, being worse in the morning and at night, or when they had to exert 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)

Individuals with AECOPDs 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., walking, climbing stairs, dressing, personal hygiene) "It is very hard to breathe, I can't climb the stairs." (Mary, 67); instrumental (e.g., doing household activities, buying groceries, talking, getting transportation) "... I can't even leave the house to catch the bus" (Mary, 67); and advanced (e.g., working, fishing, singing, going out with friends).

AECOPDs also resulted in social constraints. Participants felt that they were not able to keep up with their peers, felt isolated, were 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. Not for me, even less for the others." (Ethan, 58)

The AECOPDs impacted participants' psychological and emotional well-being. Individuals with AECOPD mentioned feeling down, scared, anxious, nervous, and frustrated and had 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 AECOPDs impacted not only people with AECOPDs but also their families.

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

Dealing with Acute Exacerbations of COPD

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

A dichotomy emerged regarding dependency on others, with participants reporting the need to rely on family for support with 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 an AECOPD they do fewer daily activities, perform everything more slowly, and feel the need for taking breaks. They also plan their routines depending on how they are feeling and try to compensate for their symptoms by using breathing strategies and laying down barely moving. One participant reported using LTOT but not feeling dyspnea 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 an Acute Exacerbation of COPD

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

The main needs of participants were focused 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 drew attention to:

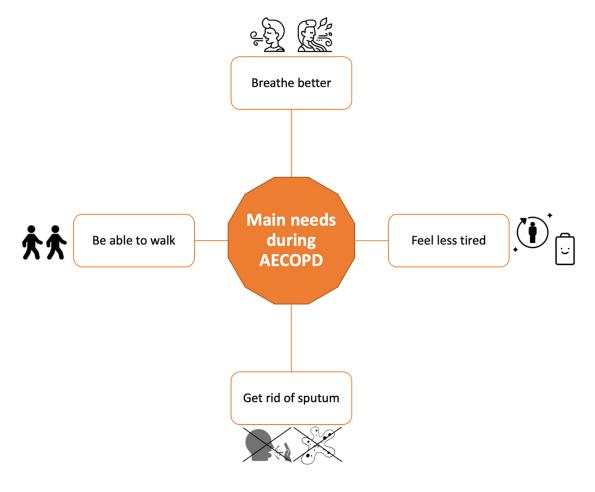
"Hmm... I would like to be able to walk like I used to walk." (Michael. 58)

Figure 2. Thematic Map for: Dealing with an Acute Exacerbation of COPD



AECOPD=acute exacerbation of chronic obstructive pulmonary disease

Figure 3. Thematic Map for: Main Needs During an Acute Exacerbation of COPD



AECOPD=acute exacerbation of chronic obstructive pulmonary disease

(Un)certainty about Pulmonary Rehabilitation

Individuals with AECOPDs with previous PR contact shared their (un)certainty about PR through 5 subthemes: lack of knowledge, get better, exercises, design and timing, and trust in health professionals (Figure 4). Individuals naive to PR had more difficulties addressing this theme and the 3 subthemes that emerged for this group were: lack of knowledge, exercises, and design and timing.

Lack of knowledge about PR was perceived by both participants with previous PR contact and those individuals 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, individuals with AECOPDs 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

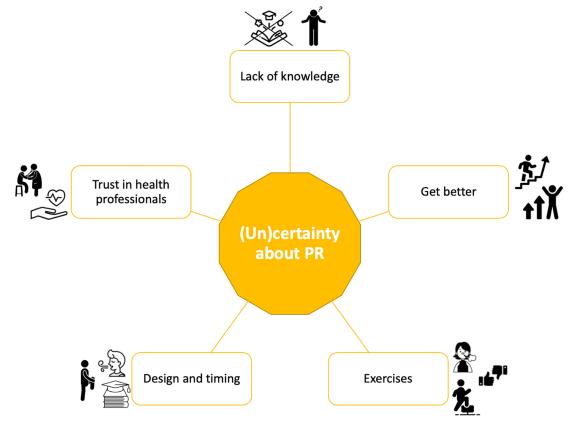
better." (Thomas, 56)

Conflicting ideas regarding exercises emerged, with 1 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. Individuals with AECOPDs 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 something similar to a stability program. One participant felt that it would be better to

Figure 4. Thematic Map for: (Un)certainty about Pulmonary Rehabilitation



PR=pulmonary rehabilitation

wait a few days to relieve 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, individuals 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 for 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 individuals' experiences during mild to moderate AECOPDs, namely the exacerbation's 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 individuals with mild to moderate AECOPDs, conducted at the onset of an exacerbation.

AECOPDs 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, 14,20,41-43 emphasizing the heterogeneity of exacerbations' clinical presentation and the need for a comprehensive symptoms' assessment. Limitations performing activities of daily living affect different dimensions than those reported by people with severe AECOPDs, 42 with impacts also occurring on the advanced activities (e.g., work). Surprisingly, people with AECOPDs 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.

AECOPDs further impacted individuals on a social, psychological, emotional, and family level. Our study reinforces findings from existing literature, 14,20 and adds that people with mild to moderate AECOPDs also feel ashamed of having symptoms in front of others, have 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, 44,45 and is often neglected. 14,46

To deal with AECOPDs, 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. ^{14,20,41} Since physical activity is the best predictor of mortality in this population, ⁴⁷ breaking this dyspnea-inactivity vicious circle ⁴⁸ must be a goal of treatment strategies. Moreover, during AECOPDs people demand additional support to perform their tasks, ¹⁴ but there is a dichotomy between the individuals who rely on their network for help and the individuals who do not want to be dependent, highlighting the need to provide formal support to these people and their families. ^{49,50}

In line with previous literature,^{20,42} the main needs reported during AECOPDs 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 PR programs that include not only exercise, education, and psychosocial support, but also breathing techniques.²⁶

Both individuals with AECOPDs naive to PR and with previous PR contact (stable disease) reported a lack of knowledge on how PR should be delivered during an AECOPD. This highlights the need to raise awareness for PR and educate the population about what it is and its benefits,²⁷ and suggests that education on PR might enhance participation. Similarly, to previous findings, in different severities of AECOPDs and treatment settings,^{27,28} most participants considered it important to have an individualized program, including exercise training, breathing techniques, and education. There was some uncertainty regarding the timing and intensity of the program.

In summary, we found that mild to moderate AECOPDs have a negative impact on several aspects of people's lives and share some similarities with reports from those individuals hospitalized with a severe AECOPD, emphasizing the importance of also providing proper interventions to manage mild to moderate AECOPDs.⁵¹ The multitude of impacts and needs reported during the AECOPD require a comprehensive assessment, which would allow for the identification of the treatable traits to be addressed during a personalized

PR program.^{52,53} Previous literature has shown that PR is a safe intervention for the management of AECOPDs that targets several of these treatable traits, namely, physical activity, exercise capacity, muscle weakness, dyspnea, and emotional burden.^{23,26,54,55} To address the complexity of individuals with AECOPDs, an interdisciplinary team composed of physicians, physiotherapists, respiratory therapists, nurses, psychologists, behavioral specialists, occupational therapists, social workers, and a care coordinator seems to be necessary.^{28,56-58}

Methodological Considerations

This study has several 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 to 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 to the acute phase⁵⁹ individuals were experiencing, and the tiredness they felt.⁶⁰ The sample included was small, but consistent with qualitative studies^{41,61,62} 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 regarding the use of colloquial expressions or proverbs. However, we believe the main themes and conclusions are not affected by the translation process.

Conclusion

Mild to moderate AECOPDs have a negative impact on individuals' lives, even though no hospital admission is required. Symptoms were reported as the main concern, thus interventions focusing on symptomatic relief are needed. Further physical, functional, psychological, emotional, social, and family level impacts were noted, highlighting the importance of comprehensive assessments and interdisciplinary PR programs. Individuals with AECOPDs considered PR beneficial but lacked knowledge about the intervention, highlighting the need to raise awareness for PR within this population. This study contributes with a foundation for the development of tailored and meaningful personcentered interventions during AECOPDs.

Acknowledgments

Author contributions: All authors contributed to the 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 wrote the first draft of the manuscript, and all authors provided critical review of the manuscript and approved the final revision.

The authors would like to acknowledge the support from the clinicians at Unidade Local de Saúde de Matosinhos and Centro Hospitalar do Baixo Vouga in recruiting participants to this study. We are also grateful to all the individuals with COPD who agreed to participate in this study.

Declaration of Interest

The authors have no conflicts of interest to declare.

References

- Global Initiative for Chronic Obstructive Lung Disease (GOLD). Global strategy for the diagnosis, management, and prevention of chronic obstructive pulmonary disease, 2022 report. GOLD website. Published 2022. Accessed December 20, 2021. https://goldcopd.org/2022-gold-reports-2/
- 2. Wedzicha JA, Miravitlles M, Hurst JR, et al. Management of COPD exacerbations: a European Respiratory Society/American Thoracic Society guideline. *Eur Respir J.* 2017;49(3):1600791. doi: https://doi.org/10.1183/13993003.00791-2016
- 3. Celli BR, Fabbri LM, Aaron SD, et al. An updated definition and severity classification of COPD exacerbations: the Rome proposal. *Am J Respir Crit Care Med.* 2021;204(11):1251-1258. doi: https://doi.org/10.1164/rccm.202108-1819PP
- Boer L, Bischoff E, Borgijink X, et al. 'Exacerbation-free time' to assess the impact of exacerbations in patients with chronic obstructive pulmonary disease (COPD): a prospective observational study. NPJ Prim Care Respir Med. 2018;28(1):1-6. doi: https://doi.org/10.1038/s41533-018-0079-5
- Seemungal TA, Hurst JR, Wedzicha JA. Exacerbation rate, health status and mortality in COPD-a review of potential interventions. *Int J Chron Obstruct Pulmon Dis.* 2009;4:203-223. doi: https://doi.org/10.2147/COPD.S3385
- Anzueto A. Impact of exacerbations on COPD. Eur Respir Rev. 2010;19(116):113-118. doi: https://doi.org/10.1183/09059180.00002610
- 7. Celli BR, MacNee W, Agusti A, et al. Standards for the diagnosis and treatment of patients with COPD: a summary of the ATS/ERS position paper. *Eur Respir J.* 2004;23(6):932-946. doi: https://doi.org/10.1183/09031936.04.00014304
- Wedzicha JA, Seemungal TA. COPD exacerbations: defining their cause and prevention. *Lancet*. 2007;370(9589):786-796. doi: https://doi.org/10.1016/S0140-6736(07)61382-8
- 9. Mathioudakis AG, Abroug F, Agusti A, et al. Core outcome set for the management of acute exacerbations of chronic obstructive pulmonary disease: the COS-AECOPD ERS task force study protocol. *ERJ Open Res.* 2020;6(3):00193-2020. doi: https://doi.org/10.1183/23120541.00193-2020
- Agustí A, Calverley PM, Decramer M, Stockley RA, Wedzicha JA. Prevention of exacerbations in chronic obstructive pulmonary disease: knowns and unknowns. *Chronic Obstr Pulm Dis.* 2014;1(2):166-184. doi: https://doi.org/10.15326/jcopdf.1.2.2014.0134

- Lopez-Campos JL, Agustí A. Heterogeneity of chronic obstructive pulmonary disease exacerbations: a two-axes classification proposal. *Lancet Respir Med.* 2015;3(9):729-734. doi: https://doi.org/10.1016/S2213-2600(15)00242-8
- 12. Pavord ID, Jones PW, Burgel P-R, Rabe KF. Exacerbations of COPD. *Int J Chron Obstruct Pulmon Dis.* 2016;11(Spec Iss):21-30. doi: https://doi.org/10.2147/COPD.S85978
- 13. Zhou A, Zhou Z, Zhao Y, Chen P. The recent advances of phenotypes in acute exacerbations of COPD. *Int J Chron Obstruct Pulmon Dis.* 2017;12:1009-1018. doi: https://doi.org/10.2147/COPD.S128604
- Kessler R, Ståhl E, Vogelmeier C, et al. Patient understanding, detection, and experience of COPD exacerbations: an observational, interview-based study. *Chest.* 2006;130(1):133-142. doi: https://doi.org/10.1378/chest.130.1.133
- 15. Adams R, Chavannes N, Jones K, Østergaard MS, Price D. Exacerbations of chronic obstructive pulmonary disease-a patients' perspective. *Prim Care Respir J.* 2006;15(2):102-109. doi: https://doi.org/10.1016/j.pcrj.2006.01.003
- 16. Chin ED. The COPD exacerbation experience: a qualitative descriptive study. *Appl Nurs Res.* 2017;38:38-44. doi: https://doi.org/10.1016/j.apnr.2017.09.005
- 17. Williams V, Hardinge M, Ryan S, Farmer A. Patients' experience of identifying and managing exacerbations in COPD: a qualitative study. *NPJ Prim Care Respir Med.* 2014;24(1):1-6. doi: https://doi.org/10.1038/npjpcrm.2014.62
- 18. Jager KJ, Tripepi G, Chesnaye NC, Dekker FW, Zoccali C, Stel VS. Where to look for the most frequent biases? *Nephrology*. 2020;25(6):435-441. doi: https://doi.org/10.1111/nep.13706
- 19. Smith SM, Jan S, Descallar J, Marks GB. An investigation of methods to improve recall for the patient-reported outcome measurement in COPD patients: a pilot randomised control trial and feasibility study protocol. *Pilot Feasibility Stud.* 2019;5(1):1-8. doi: https://doi.org/10.1186/s40814-019-0475-9
- 20. Miravitlles M, Anzueto A, Legnani D, Forstmeier L, Fargel M. Patient's perception of exacerbations of COPD-the PERCEIVE study. *Respir Med.* 2007;101(3):453-460. doi: https://doi.org/10.1016/j.rmed.2006.07.010
- 21. Nici L. Improving uptake of pulmonary rehabilitation after a chronic obstructive pulmonary disease exacerbation. *Ann Am Thorac Soc.* 2019;16(9):1119–1121. doi: https://doi.org/10.1513/AnnalsATS.201906-429ED
- Vincent EE, Chaplin EJ, Williams JE, et al. Experiences of patients undergoing pulmonary rehabilitation during an exacerbation of chronic respiratory disease. *Chron Respir Dis.* 2017;14(3):298-308. doi: https://doi.org/10.1177/1479972317695812

- 23. Puhan MA, Gimeno-Santos E, Cates CJ, Troosters T. Pulmonary rehabilitation following exacerbations of chronic obstructive pulmonary disease. *Cochrane Database Syst Rev.* 2016;12:CD005305. doi: https://doi.org/10.1002/14651858.CD005305.pub4
- 24. Spruit MA, Singh SJ, Garvey C, et al. An official American Thoracic Society/European Respiratory Society statement: key concepts and advances in pulmonary rehabilitation. *Am J Respir Crit Care Med.* 2013;188(8):e13-e64. doi: https://doi.org/10.1164/rccm.201309-1634ST
- 25. Spruit MA, Singh SJ, Rochester CL, et al. Pulmonary rehabilitation for patients with COPD during and after an exacerbation-related hospitalisation: back to the future? *Eur Respir J.* 2018;51(1):1701312. doi: https://doi.org/10.1183/13993003.01312-2017
- 26. Machado A, Silva PM, Afreixo V, Caneiras C, Burtin C, Marques A. Design of pulmonary rehabilitation programmes during acute exacerbations of COPD: a systematic review and network meta-analysis. *Eur Respir Rev.* 2020;29(158):200039. doi: https://doi.org/10.1183/16000617.0039-2020
- 27. Janaudis-Ferreira T, Tansey CM, Harrison SL, et al. A qualitative study to inform a more acceptable pulmonary rehabilitation program after acute exacerbation of chronic obstructive pulmonary disease. *Ann Am Thorac Soc.* 2019;16(9):1158-1164. doi: https://doi.org/10.1513/AnnalsATS.201812-854OC
- 28. Oliveira A, Quach S, Alsubheen S, et al. Rapid access rehabilitation after exacerbations of COPD-A qualitative study. *Respir Med.* 2021;186:106532. doi: https://doi.org/10.1016/j.rmed.2021.106532
- 29. Barker R, Brighton LJ, Maddocks M, et al. Integrating home-based exercise training with a hospital at home service for patients hospitalised with acute exacerbations of COPD: developing the model using accelerated experience-based co-design. *Int J Chron Obstruct Pulmon Dis.* 2021;16:1035-1049. doi: https://doi.org/10.2147/COPD.S293048
- 30. Partridge MR, Dal Negro RW, Olivieri D. Understanding patients with asthma and COPD: insights from a European study. *Prim Care Respir J.* 2011;20(3):315-323. doi: https://doi.org/10.4104/pcrj.2011.00056
- 31. National Institutes of Health, National Library of Medicine. Pulmonary rehabilitation during acute exacerbations of chronic obstructive pulmonary disease: a mixed-methods approach; NCT03751670. Clinical trials.gov website. Published November 2018. Accessed December 2021. https://clinicaltrials.gov/ct2/ show/NCT03751670
- 32. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19(6):349-357. doi:https://doi.org/10.1093/intqhc/mzm042

- 33. Creswell JW. Qualitative Inquiry & Research Design. 2nd Ed. Sage Publications, Inc.; 2007. https://www.academia.edu/33813052/Second_Edition_QUALITATIVE_INQUIRY_and_RESEARCH_DESIGN_Choosing_Among_Five_Approaches
- 34. McAuley H, Hadley K, Elneima O, et al. COPD in the time of COVID-19: an analysis of acute exacerbations and reported behavioural changes in patients with COPD. *ERJ Open Res.* 2021;7(1):00718-2020. doi: https://doi.org/10.1183/23120541.00718-2020
- 35. Oliveira AL, Marques AS. Outcome measures used in pulmonary rehabilitation in patients with acute exacerbation of chronic obstructive pulmonary disease: a systematic review. *Phys Ther*. 2018;98(3):191-204. doi: https://doi.org/10.1093/ptj/pzx122
- 36. Jones PW, Tabberer M, Chen W-H. Creating scenarios of the impact of COPD and their relationship to COPD Assessment Test (CATTM) scores. *BMC Pulm Med.* 2011;11(1):1-7. doi: https://doi.org/10.1186/1471-2466-11-42
- 37. Gill P, Stewart K, Treasure E, Chadwick B. Methods of data collection in qualitative research: interviews and focus groups. *Br Dent J.* 2008;204(6):291-295. doi: https://doi.org/10.1038/bdj.2008.192
- 38. Slevin P, Kessie T, Cullen J, Butler MW, Donnelly SC, Caulfield B. A qualitative study of clinician perceptions regarding the potential role for digital health interventions for the management of COPD. *Health Informatics J.* 2021;27(1):1460458221994888. doi: https://doi.org/10.1177/1460458221994888
- 39. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol.* 2006;3(2):77-101. doi: https://doi.org/10.1191/1478088706qp063oa
- 40. Lincoln YS, Guba EG. Naturalistic Inquiry. Sage; 1985..
- 41. Barnes N, Calverley PM, Kaplan A, Rabe KF. Chronic obstructive pulmonary disease and exacerbations: patient insights from the global hidden depths of COPD survey. *BMC Pulm Med*. 2013;13(1):1-11. doi: https://doi.org/10.1186/1471-2466-13-54
- 42. Jørgensen L, Eikhof KD, Jensen MH, Størkersen ML, Andreasen J. Patients' experiences following acute admission due to COPD exacerbation. A qualitative interview study. *Int Emerg Nurs*. 2021;58:101054. doi: https://doi.org/10.1016/j.ienj.2021.101054
- Parker C, Voduc N, Aaron S, Webb K, O'Donnell D. Physiological changes during symptom recovery from moderate exacerbations of COPD. *Eur Respir J.* 2005;26(3):420-428. doi: https://doi.org/10.1183/09031936.05.00136304

- 44. Melhem O, Savage E, Al Hmaimat N, Lehane E, Fattah HA. Symptom burden and functional performance in patients with chronic obstructive pulmonary disease. *Appl Nurs Res.* 2021:151510. doi: https://doi.org/10.1016/j.apnr.2021.151510
- 45. Reijnders T, Schuler M, Jelusic D, et al. The impact of loneliness on outcomes of pulmonary rehabilitation in patients with COPD. *COPD*. 2018;15(5):446-453. doi: https://doi.org/10.1080/15412555.2018.1471128
- 46. Dury R. COPD and emotional distress: not always noticed and therefore untreated. *Br J Community Nurs*. 2016;21(3):138-141. doi: https://doi.org/10.12968/bjcn.2016.21.3.138
- 47. Waschki B, Kirsten A, Holz O, et al. Physical activity is the strongest predictor of all-cause mortality in patients with COPD: a prospective cohort study. *Chest.* 2011;140(2):331-342. doi: https://doi.org/10.1378/chest.10-2521
- 48. Ramon MA, Ter Riet G, Carsin A-E, et al. The dyspnoea-inactivity vicious circle in COPD: development and external validation of a conceptual model. *Eur Respir J.* 2018;52(3):1800079. doi: https://doi.org/10.1183/13993003.00079-2018
- Miravitlles M, Peña-Longobardo LM, Oliva-Moreno J, Hidalgo-Vega Á. Caregivers' burden in patients with COPD. *Int J Chron Obstruct Pulmon Dis.* 2015;10(1):347-356. doi: https://doi.org/10.2147/COPD.876091
- Nakken N, Janssen DJ, van den Bogaart EH, et al. Informal caregivers of patients with COPD: home sweet home? Eur Respir Rev. 2015;24(137):498-504. doi: https://doi.org/10.1183/16000617.00010114
- 51. Sato M, Chubachi S, Sasaki M, et al. Impact of mild exacerbation on COPD symptoms in a Japanese cohort. *Int J Chron Obstruct Pulmon Dis.* 2016;11(1):1269-1278. doi: https://doi.org/10.2147/COPD.S105454
- Spruit MA, Wouters EF. Organizational aspects of pulmonary rehabilitation in chronic respiratory diseases. *Respirology*. 2019;24(9):838-843. doi: https://doi.org/10.1111/resp.13512
- 53. Augustin IM, Spruit MA, Franssen FM, Gaffron S, van Merode F, Wouters EF. Incorporating comprehensive assessment parameters to better characterize and plan rehabilitation for persons with chronic obstructive pulmonary disease. *J Am Med Dir Assoc.* 2020;21(12):1986-1991.E3. doi: https://doi.org/10.1016/j.jamda.2020.05.026
- 54. Rzadkiewicz M, Bråtas O, Espnes GA. What else should we know about experiencing COPD? A narrative review in search of patients' psychological burden alleviation. *Int J Chron Obstruct Pulmon Dis.* 2016;11(1):2295-2304. doi: https://doi.org/10.2147/COPD.8109700

- 55. Ryrsø CK, Godtfredsen NS, Kofod LM, et al. Lower mortality after early supervised pulmonary rehabilitation following COPD-exacerbations: a systematic review and meta-analysis. *BMC Pulm Med.* 2018;18(1):1-18. doi: https://doi.org/10.1186/s12890-018-0718-1
- 56. Hill NS. Pulmonary rehabilitation. *Proc Am Thorac Soc.* 2006;3(1):66-74. doi: https://doi.org/10.1513/pats.200511-121JH
- 57. Spruit MA, Pitta F, Garvey C, et al. Differences in content and organisational aspects of pulmonary rehabilitation programmes. *Eur Respir J.* 2014;43(5):1326-1337. doi: https://doi.org/10.1183/09031936.00145613
- 58. Troosters T, Blondeel A, Janssens W, Demeyer H. The past, present and future of pulmonary rehabilitation. *Respirology*. 2019;24(9):830-837. doi: https://doi.org/10.1111/resp.13517
- 59. Bakhit M, Del Mar C, Gibson E, Hoffmann T. Exploring patients' understanding of antibiotic resistance and how this may influence attitudes towards antibiotic use for acute respiratory infections: a qualitative study in Australian general practice. *BMJ Open.* 2019;9(3):e026735.

 doi: https://doi.org/10.1136/bmjopen-2018-026735
- 60. Strang S, Ekberg-Jansson A, Henoch I. Experience of anxiety among patients with severe COPD: a qualitative, in-depth interview study. *Palliat Support Care*. 2014;12(6):465-472. doi: https://doi.org/10.1017/S1478951513000369
- 61. Sim J, Saunders B, Waterfield J, Kingstone T. Can sample size in qualitative research be determined a priori? *Int J Soc Res Methodol.* 2018;21(5):619-634. doi: https://doi.org/10.1080/13645579.2018.1454643
- 62. Vasileiou K, Barnett J, Thorpe S, Young T. Characterising and justifying sample size sufficiency in interview-based studies: systematic analysis of qualitative health research over a 15-year period. *BMC Med Res Methodol.* 2018;18(1):1-18. doi: https://doi.org/10.1186/s12874-018-0594-7