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ORIGINAL ARTICLE

Experiences and challenges of caregivers for patients with chronic obstructive pulmonary disease during six months post-hospital discharge: Qualitative analysis

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ABSTRACT

Background and aim: Chronic obstructive pulmonary disease (COPD) is a progressive respiratory disease with a high incidence of exacerbations and hospitalisation. Caregivers, after hospital discharge, play a central role in the management of the disease without often adequate support. This study aims to explore the experiences of caregivers of patients with COPD in the six months after hospital discharge, identifying the main difficulties encountered and the impact of these challenges on the caregiver's quality of life.
Methods: A qualitative phenomenological study based on the Colazzi approach was conducted. Twenty-three caregivers who had cared for patients with COPD discharged from Italian hospitals for at least 6 months after discharge were recruited. Semi-structured, question-guided interviews were used to collect data, which were subsequently transcribed and analysed to identify the main themes underlying their experience.
Results: Four main themes emerged from the qualitative analysis: 1) Challenges in daily management of the disease, 2) Emotional and psychological impact, 3) Relationship with health professionals and 4) Impact on quality of life. Caregivers described difficulties in administering therapy, managing symptoms and making

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environmental adjustments. They also reported high levels of stress, anxiety and a sense of overload, as well as difficulties in communicating with the healthcare team and finding the resources needed for optimal care. **Conclusions:** The experiences of caregivers of patients with COPD highlight the need for greater practical and emotional support from healthcare professionals, especially regarding disease management and psychological well-being. (www.actabiomedica.it)

Key words: Chronic Obstructive Pulmonary Disease, caregiver, disease management, emotional impact, quality of life, nursing education

Background

Chronic Obstructive Pulmonary Disease (COPD) is one of the leading causes of morbidity and mortality worldwide, with an estimated global prevalence of around 12% in the population over 40 years of age (1). COPD is projected to become the third leading cause of death globally by 2030 (2). Characterized by progressive airway obstruction and chronic inflammation, COPD also features a high frequency of exacerbations, which worsen prognosis and often lead to repeated hospitalizations (2).Within the first 30 days post-hospital discharge, 20-30% of patients are readmitted, and this risk remains elevated in the following months, often due to respiratory infections, environmental exposures, and poor adherence to prescribed therapies (3,4). Smoking and air pollution are the main causes of COPD (5). Symptoms of COPD include breathlessness, chronic cough, sputum production, wheezing, reduced exercise tolerance, fatigue, and worsening symptoms in the morning (2). These symptoms tend to worsen as the disease progresses and lead to a progressive loss of functional independence, reducing their ability to perform daily activities independently. The course of COPD is characterised by exacerbations and fluctuations in symptoms, requiring both patients and caregivers to be able to respond promptly (6). Given the unpredictable, progressive and chronic nature of COPD, the role of the caregiver can be long, burdensome and constantly changing; the caregiver must adapt to the patient's changing condition, and manage the disease as it evolves (7). The daily management of COPD requires vigilant administration of medications, symptom monitoring, respiratory complication management, coordination with health services and the ability to manage complex daily care requirements (8–10). It is estimated that more than 70% of patients with advanced COPD rely on informal carers (11), generally spouses, children or close relatives, who assume a central role, especially in the initial months following hospital discharge (12,13). The interaction between the quality of life of the patient and the carer is interdependent. Factors affecting the patient, including functional dependence, duration of illness, comorbidities and emotional distress, directly influence the carer's burden, while the carer's stress can negatively affect patient outcomes (14). In fact, the study by Cai et al, (15) reported a significant positive correlation between caregiver contribution to disease management and patients' physical and mental quality of life. Similarly, the study by Ivziku et al., (10) found that caregiver psychological distress affects patients' physical well-being as well as caregivers' own mental well-being. Despite the essential contribution of carers, their needs are often overlooked, as healthcare professionals focus their attention on the patient, neglecting the carer's preparation, mental state and ability to perform the required role (11). This multifaceted and complex role, particularly in the absence of adequate education, requires significant organisational, emotional, and practical effort from caregivers (1). Given the essential role of family caregivers in managing COPD, understanding and addressing their needs is crucial to reducing caregiver stress, improving their quality of life, and promoting effective patient care. Previous qualitative studies on caregivers of COPD patients focused mainly on general caregiving experiences (9), without specifically investigating the first six months after hospital discharge, a period characterised by greater complexity and vulnerability (16). Therefore, the purpose of this article is to explore the experiences of caregivers for patients with COPD, the main challenges they encounter while providing care, and the impact of these challenges on their quality of life within the first six months after hospital discharge.

Methods

This study adopted a descriptive phenomenological approach, applied through semi-structured interviews and data analysis according to Colaizzi's method (1978) (17), integrated with the epistemological principles proposed by Mortari (2007) (18). This approach rests on the assumption that human experience can be best understood through the direct narration of those involved, allowing for an in-depth exploration of the meaning of lived experiences and the challenges caregivers face.

Data analysis followed the original seven-step procedure described by Colaizzi: (1) repeated reading of the transcripts to obtain a general sense of the content; (2) extraction of significant statements; (3) formulation of meanings; (4) organisation of meanings into clusters and themes; (5) development of an exhaustive description; (6) identification of the fundamental structure of the phenomenon; and (7) validation of the findings through participant feedback (member checking). To ensure methodological rigour, bracketing was applied throughout the analysis, with researchers consciously suspending pre-understandings. Analyst triangulation was implemented: two researchers independently coded the transcripts and compared emerging themes. Data saturation was achieved at the twenty-second interview, when no new relevant meanings emerged.

Participants were interviewed with the guiding question: *"Can you describe the experiences and challenges you encountered during home care for your relative in the six months following their hospital discharge?"* This open-ended interview format provided an environment in which caregivers could freely express themselves, offering detailed accounts of their experiences. The sampling method employed was purposive or convenience-based. Participants were recruited according to specific criteria, such as continuous, unpaid involvement in patient care for at least six months following a hospital admission. This type of sampling does not aim for statistical representativeness but instead seeks to deepen understanding of the phenomenon under study. Interviews were conducted in selected Italian hospitals, specifically in pulmonology, geriatrics, and general medicine departments, with caregivers of patients with COPD between June 2023 and June 2024. This setting enabled timely engagement with caregivers, facilitating participant access and ensuring the relevance of shared experiences. The interviews, conducted by two PhD female experienced researchers (an interviewer and an observer) in a comfortable, distraction-free environment, were audio-recorded with participants' informed consent, fully transcribed for analysis, and repeatedly reviewed to ensure familiarity with the data and capture participants' experiences as comprehensively as possible. Phrases or expressions reflecting significant aspects of caregivers' experiences were identified, particularly those relating to challenges in patient management, with each phrase distilled into meanings that represented the essence of the narrated experience. These meanings were grouped into common or recurring themes, which were then elaborated upon to provide a comprehensive overview of the caregivers' post-discharge experiences. In the final phase, researchers conducted a critical analysis of the themes, aiming to capture emotional, psychological, and practical dimensions. This phase included crafting a coherent narrative summarizing the primary experiences shared by caregivers, highlighting key areas of relevance and common challenges (17). Findings from this last phase were then presented to participants for validation, allowing them to confirm the accuracy of the interpretations. This process provided a rich, detailed understanding of the challenges faced by caregivers in the six months following their relative's hospital discharge, yielding valuable insights for developing more targeted support interventions.

Ethical considerations

Potential participants received both written and verbal information regarding the study objectives and data collection procedures, including the audio recording. It was clarified that participants' identities would remain anonymous in all records and documentation. Those who agreed to participate provided signed consent, both for their involvement in the study and for the handling of personal data. Specific ethical considerations related to interviews, such as informed consent and confidentiality, were carefully addressed. Moderators highlighted the importance of confidentiality, fostering an environment for open discussion while ensuring prevention of any potential ethical misconduct (World Medical Association (WMA). Declaration of Helsinki: ethical principles for medical research involving human subjects. JAMA. 2013;310:2191-2194. doi:10.1001/jama.2013.281053).

Results

Characteristics of participants

A total of 23 interviews were conducted, each averaging 30 minutes in duration. The sample was predominantly composed of individuals aged 41-60 years (56.5%, n = 13), female (56.5%, n = 13), and primarily partners or spouses of the patients they cared for (65.2%, n = 15). Most caregivers resided in urban areas (78.3%, n = 18), were employed (52.2%, n = 12), and held a medium to high level of education (60.9%, n = 14). Regarding the time dedicated to assisting patients with COPD, 43.5% (n = 10) of caregivers provided approximately 10-20 hours of care per week (Table 1).

Based on the caregivers' accounts, patients had varying levels of functional autonomy. 15 caregivers described significant limitations in their patients' daily activities, particularly in relation to mobility, personal hygiene and management of respiratory symptoms, which required constant support. 3 caregivers described their family members as having partial residual autonomy in daily activities, while 5 reported conditions of high dependency. The qualitative data analysis revealed a range of themes and sub-themes that capture the personal experiences and specific challenges caregivers faced during the six-month period following hospital discharge. The main themes and sub-themes identified are reported in Table 2.

These themes and sub-themes capture the primary experiences and challenges faced by caregivers over the six months following their family member's hospital discharge.

Theme 1: Challenges in daily disease management

Challenges in managing the daily aspects of the disease emerged as a predominant theme in interviews with caregivers of patients suffering from Chronic Obstructive Pulmonary Disease (COPD). These difficulties pertain to various facets of daily life and reflect the complexities inherent in caring for a chronic, complex illness.

Sub-Theme 1: Difficulties in administering therapy

The difficulties in administering therapy were described by caregivers in ways that highlight the complexities and daily challenges they face. Here are some caregiver quotes illustrating this point:

1. "Managing the medications is really complicated. The patient has a long list of prescriptions, and every day I have to make sure they take everything at the right time. I don't always have the time or energy to keep up with all the changes and check that everything is in order. Sometimes I forget a dose, and that worries me a lot." (C2 GS)
2. "It's not just a matter of administering the medicines, but also using the nebulizer and inhaler correctly. Every time there is a change in the type of medication or dosage, I have to consult the doctor to make sure I'm doing everything right." (C4 VB)
3. "The patient often experiences side effects from the medications, and I don't always understand if it's normal or if I should contact the doctor. It's difficult to keep track of all the reactions and know when it's time to

Table 1. Socio-Demographic Characteristics of Caregivers

Variable	Category	Number (n)	Percentage (%)
Gender	Male	10	43.5
	Female	13	56.5
Age (years)	18-30	3	13.0
	31-40	5	21.7
	41-50	7	30.4
	51-60	6	26.1
	>60	2	8.7
Relationship with the Patient	Spouse/Partner	15	65.2
	Son/Daughter	5	21.7
	Sibling	2	8.7
	Other	1	4.3
Employment Status	Full-time Employed	8	34.8
	Part-time Employed	4	17.4
	Unemployed	6	26.1
	Homemaker	5	21.7
Education Level	High School	7	30.4
	Bachelor's Degree	8	34.8
	Master's Degree	6	26.1
	Other	2	8.7
Residence	Urban	18	78.3
	Suburban	4	17.4
	Rural	1	4.3
Weekly Caregiving Hours	<10 hours	5	21.7
	10-20 hours	10	43.5
	21-30 hours	6	26.1
	>30 hours	2	8.7

Table 2. Main Themes and Sub-Themes Identified

Theme	Sub-Themes
Challenges in Daily Disease Management	• Difficulties in Administering Therapy
	• Symptom Management
	• Environmental Adaptations
Emotional and Psychological Impact	• Stress and Anxiety
	• Exhaustion and Sense of Overload
Relationship with Healthcare Professionals	• Communication with Medical and Nursing Teams
	• Access to Resources and Training
	• Ongoing Support
Impact on Quality of Life	• Difficulties with Daily Activities
	• Changes in Family Life
	• Concerns for the Future

intervene… it's not always easy to tell if the patient is using them correctly. This increases my stress." (C11 IP)

4. "Sometimes, the patient refuses to take the medications or has trouble tolerating them. This makes it even harder to maintain a consistent care regimen, and it makes me feel like I'm failing in my role as a caregiver." (C15 ER)

These quotes reflect the complex difficulties caregivers face in administering therapy, emphasizing challenges in managing prescriptions, using medical devices correctly, and coping with the impact of side effects.

SUB-THEME 2: SYMPTOM MANAGEMENT

The difficulties in symptom management were expressed by caregivers through various statements that highlight the daily challenges and concerns related to the patient's condition. Here are five quotes that illustrate this point:

1. "Every day is a struggle to control the patient's dyspnea. When they start having difficulty breathing, I feel completely helpless and never know if I'm doing enough to alleviate their symptoms… Sudden respiratory crises are always a moment of panic… I don't always know what to do, and I often have to call the doctor or go to the emergency room, which is exhausting both physically and emotionally." (C1GT)
2. "The patient's persistent cough is extremely debilitating. I try to find ways to relieve it, but nothing seems to really work, and that frustrates me a lot." (C10DD)
3. "Monitoring the patient's symptoms is a full-time job. Every little change in their breathing or condition makes me worry and forces me to make quick decisions, often without knowing if I'm doing the right thing." (C19NO)
4. "There's always the fear of a worsening of symptoms, especially at night. Every time the patient wakes up with difficulty breathing, I wake up too and worry about their safety and what to do in case of an emergency." (C21MM)

These statements reflect the daily challenges that caregivers face in managing COPD symptoms, highlighting constant concern, a sense of helplessness during crises, and the emotional toll of ongoing symptom management.

SUB-THEME 3: ENVIRONMENTAL ADJUSTMENTS

Caregivers described several environmental adjustments necessary to improve the comfort and safety of patients with COPD. Here are five quotes illustrating these adaptations:

1. "I installed a humidifier in every room because the dry air seems to aggravate the patient's cough. It was a significant investment, but I've seen improvements in their respiratory comfort." (C12PA)
2. "I had to redesign the living room to make space for their respirator and other medical devices. This involved moving furniture and creating a dedicated area for their needs, but it's essential for their comfort." (C18CR)
3. "To reduce the patient's fatigue, we've placed everything within reach, like medications and inhalation tools. Every time they have to move to get something, it's an extra effort that can tire them out." (C6GG)

These quotes highlight how caregivers adapt the home environment to meet the specific needs of patients, improving safety, comfort, and practicality in daily COPD management.

Theme 2: Emotional and psychological impact

The emotional and psychological impact of caring for a family member with Chronic Obstructive Pulmonary Disease (COPD) is profound and multifaceted. Caregivers often face a significant emotional burden that includes stress, anxiety, and feelings of exhaustion. The constant concern for the patient's health and the management of respiratory crises contribute to a daily sense of anxiety and fear. Additionally, the ongoing sense of responsibility and the challenge of balancing the patient's needs with their personal requirements can lead to considerable physical and emotional burnout.

Many caregivers report feelings of isolation and loneliness due to a lack of external support or adequate social networks. Managing the illness requires continuous commitment and often involves personal and professional sacrifices, which can further exacerbate feelings of stress and frustration. This combination of emotional and psychological factors underscores the importance of providing adequate support and resources to help caregivers manage their roles and maintain their well-being.

Theme 2: Emotional and psychological impact

Sub-Theme 2.1: Stress and anxiety

Caregivers often express the stress and anxiety arising from managing a family member with COPD through statements that reflect their concerns and the emotional burden they face daily.

1. "The weight of having to manage emergencies and complications of the illness has left me completely exhausted... I feel like I never have a moment of peace for myself... The sense of responsibility is overwhelming. When the patient is unwell, I feel that everything depends on me, and this creates constant pressure that I can't easily bear." (C5 LR)
2. "I always worry about finances because the costs of care and medical visits are enormous... This added stress makes me feel overwhelmed and incapable of managing everything." (C8CL)
3. "The anxiety of not being able to provide the patient with the best support possible makes me feel inadequate. Every little sign of worsening in their condition sends me into a panic." (C3DM)

These quotes reflect the intense stress and anxiety that caregivers experience while facing the daily challenges of caring for a family member with COPD, highlighting the emotional burden and ongoing concerns that affect their well-being.

Sub-Theme 2.2: Exhaustion and sense of overwhelm

Experiences of exhaustion and a sense of overwhelm are common among caregivers of patients with COPD. Resilience intertwines with these feelings, manifesting in their daily lives:

1. "I feel completely exhausted... The long hours of care and the constant attention to the patient's needs leave me drained... and prevent me from doing anything else. I have sacrificed so much of my free time and energy to care for the patient that now I don't know how to recover... Every day is a challenge, and the accumulated fatigue is unsustainable." (C17IL)
2. "Sometimes I feel like I can't breathe myself. The weight of responsibility and the lack of time for myself are pushing me to my limit... I don't know how long I can last... This role was not explained to me like this... honestly, I don't know if I will continue... maybe it's better to involve someone more experienced." (C7AA)
3. "My work and daily activities have practically disappeared because I focus solely on caring for the patient... This makes me feel overwhelmed and as if I am losing control of my life." (C20AS)
4. "The pressure of having to manage everything, from medications to medical visits, without concrete help makes me feel like I'm carrying an enormous weight on my shoulders. It's hard to find a balance, and I often feel at the limit of my endurance." (C22NV)

These quotes highlight the profound exhaustion and sense of overwhelm that many caregivers experience, reflecting the physical and emotional toll of their daily responsibilities in caring for a family member with COPD.

Sub-Theme 2.3: Social support

Social support is a crucial aspect for caregivers, and their experiences vary significantly. Here's how caregivers perceive and experience social support in their situations:

1. "I feel very alone on this journey. Even though I have friends and family who want to help, they often aren't available when I really need them... The support I receive from my friends is essential, but it's limited. I can't count on them for everything, and often I find myself having to manage everything alone." (C1GT)
2. "I've found great comfort in online support groups. Talking with other caregivers makes me feel less isolated and provides me with new insights on how to cope with daily difficulties." (C16TA)
3. "My family tries to do their best, but they don't always truly understand how difficult my situation is. Sometimes, it feels like their help isn't sufficient or targeted to my real needs." (C18CR)
4. "I have sought professional help, such as counseling, to cope with the stress. This type of support has been very helpful, but it doesn't completely replace the need for more tangible support in daily life." (C14LO)

These quotes highlight the variability in social support that caregivers receive, illuminating both the gaps and sources of comfort that can influence their well-being while caring for a family member with COPD.

Theme 3: Relationship with health professionals

The relationship with health professionals is a crucial theme in the lives of caregivers of patients with Chronic Obstructive Pulmonary Disease (COPD). This relationship significantly impacts both the quality of care and the well-being of the caregivers themselves. Effective communication between caregivers and health professionals is essential for the successful management of COPD. Many caregivers report difficulties in receiving clear and detailed explanations about treatment instructions and changes to the care plan. A lack of effective communication can lead to misunderstandings regarding medication administration, use of medical devices, and symptom management. When communication is good, caregivers feel more secure and informed, but when it is insufficient, it can heighten feelings of stress and uncertainty. In summary, the relationship with health professionals plays a crucial role in caregivers' management of COPD. Effective communication, positive and accessible support, and adequate training are key elements to enhance the caregiver experience and ensure high-quality care for the patient.

SUB-THEME 3.1: COMMUNICATION WITH THE MEDICAL AND NURSING TEAM

Effective communication between caregivers and the medical and nursing team is vital for ensuring optimal care and support. In the context of managing chronic conditions like COPD, clear and consistent interactions with health professionals can significantly influence the caregiver's ability to effectively meet the patient's needs. This aspect of caregiving encompasses not only understanding medical instructions and treatment plans but also the opportunity to address concerns and receive timely support. Exploring how caregivers perceive and experience their interactions with healthcare teams offers valuable insights to improve communication strategies and overall care.

1. "Sometimes I find it difficult to get clear answers to my questions about medications and treatments. When we ask for explanations, the answers are often too technical and hard to understand... I appreciate when doctors and nurses take the time to explain things and address my concerns, but often visits are short, and I don't have the chance to discuss everything I need." (C22NV)
2. "When the patient has a crisis, I feel lost because I don't know exactly what to do. There isn't always someone available to provide immediate guidance when we are in trouble... There are times when I feel that the information is given to us in a fragmented and inconsistent manner. It's frustrating to have to go back and forth between different specialists

to get a complete picture of the situation." (C23CF)

3. "It seems to me that sometimes the doctors don't fully consider my observations and concerns regarding the patient. This makes me feel as though my role as a caregiver is not recognized or respected." (C4VB)

These statements reflect the challenges caregivers face in communicating with health professionals, highlighting the need for improved clarity, availability, and attention in providing information and support.

SUB-THEME 3.2: ACCESS TO RESOURCES AND TRAINING

The need for educational resources and training is a recurring aspect of the interaction between caregivers and health professionals. Caregivers often request adequate training to manage the complex therapeutic needs of the patient, such as the use of nebulizers and other devices. The availability of resources and proper training can significantly improve their ability to manage the disease and reduce emotional burdens. However, access to such resources may be limited, and many caregivers find themselves managing the illness with inadequate preparation.

1. "I had difficulty finding adequate resources to understand how to use medical devices correctly. It would have been helpful to have a specific training course for caregivers... We were not clearly informed about how to manage respiratory crises at home. Detailed guidance and practical training could have made a big difference." (C19NO)
2. "I looked for support online and found some useful information, but I would have liked direct access to resources provided by specialists who know the patient's specific situation... When the doctor changes the treatment plan, we don't always receive updates on how to manage new medications or new equipment. Ongoing training would have been very helpful." (C6GG)
3. "I felt abandoned when I had to deal with technical issues with the respirator. An opportunity for practical training to handle such situations would have alleviated my stress." (C7AA)

These statements reflect the difficulties caregivers encounter in accessing adequate resources and receiving practical training, underscoring the need for more structured and direct support to improve home care management.

SUB-THEME 3.3: ONGOING SUPPORT

Continuous support from health professionals is essential for caregivers. Consistent management and regular follow-ups help monitor the patient's progress and manage changes, such as adjustments to the treatment plan. However, caregivers report that the quality of follow-up can vary, with some patients receiving adequate attention while others struggle to access continuous monitoring. Ongoing and timely support can alleviate the caregiver's burden and anxiety, improving the overall effectiveness of disease management.

1. "I've noticed that follow-up after discharge is very sporadic. Not having regular contact with the doctor and nurse often leaves me uncertain about how to handle new difficulties that arise... When the patient has a sudden problem, it's hard to get a timely response from the medical team. I would need a support system that allows me to get quicker answers." (C23CF)
2. "It would be helpful to have a fixed point of contact, like a case manager nurse, who can provide ongoing assistance and answer my questions as they arise... The support we receive seems to focus only on scheduled check-ups, while daily needs and emergencies are not always well managed. Continuous support would be very valuable." (C12PA)
3. "Sometimes I need further clarification or practical help, but it seems there isn't enough support for everyday issues. More regular and systematic assistance would make a huge difference." (C5LR)

These statements reflect the need for continuous and consistent support from health professionals, highlighting caregivers' desire for regular and accessible assistance to better manage daily challenges.

In summary, the relationship with healthcare professionals plays a crucial role in the caregiver's management of COPD. Effective communication, ongoing and accessible support, and adequate training are key elements to enhance the caregiver experience and ensure high-quality care for the patient.

Theme 4: Implications for quality of life

The implications for the quality of life of caregivers of patients with Chronic Obstructive Pulmonary Disease (COPD) are significant and multifaceted. The emotional and physical burden of caregiving can profoundly affect the overall well-being of caregivers. The experience of stress, anxiety, and exhaustion associated with the continuous management of the illness contributes to a decline in quality of life. Caregivers often sacrifice their personal, professional, and social time to dedicate themselves to patient care, leading to feelings of isolation and a reduction in opportunities to engage in fulfilling activities. Moreover, the lack of adequate support and educational resources can exacerbate their stress and negatively impact their ability to cope with daily challenges. These factors can compromise their physical and mental health, diminishing their capacity to maintain a balance between personal life and caregiving responsibilities. Improving support, access to resources, and communication with health professionals is crucial for alleviating the burden on caregivers and, consequently, enhancing their quality of life.

Sub-Theme 4.1: Difficulties in daily activities

Difficulties in daily activities emerge as one of the primary challenges for caregivers of patients with COPD, who often find themselves needing to reconcile caregiving demands with their personal responsibilities. Managing the patient's symptoms and therapies requires time and energy, compromising the caregivers' ability to perform normal domestic, work, and social activities.

1. "Managing the daily activities of the patient is extremely demanding. My day is constantly interrupted by tasks such as administering medications and monitoring symptoms, bathing, ... which prevents me from engaging in other activities." (C11IP)
2. "I often have to adapt my entire daily schedule to meet the patient's needs. Simple tasks like grocery shopping or doing housework become complicated and require meticulous planning." (C17IL)
3. "I have difficulty maintaining a regular routine because the patient needs continuous assistance. This makes it almost impossible to keep personal or work commitments, and it makes me feel like my life is entirely dedicated to caregiving." (C19NO)

These statements reflect the daily challenges that caregivers face in managing the patient's daily activities, highlighting the significant impact on their time, energy, and overall well-being.

Sub-Theme 4.2: Changes to family life

Changes to family life represent one of the most significant consequences for caregivers of patients with COPD. The constant commitment required in managing the illness leads to a reorganization of family dynamics, profoundly influencing interpersonal relationships, daily routines, and the time allocated for social and personal activities.

1. "Our family life has completely changed. We have to plan every activity around the patient's needs, and often outings or vacations get canceled or postponed... I feel that my family life has become a delicate balance between the patient's needs and the necessities of other family members. This has led to a decrease in the quality of the time we spend together as a family." (C13MB)
2. "Family dynamics have been turned upside down. Most of the time is dedicated to caring for the patient, which has led to tensions and conflicts among family members who feel

neglected... Our daily routine has been drastically altered. We have to adjust meals, activities, and even sleeping habits to accommodate the patient, and this has affected how we all live together." (C9VP)
3. "I regret that our social life has almost disappeared... We can no longer participate in family gatherings or events with friends as we used to, and this has created a sense of isolation for all of us." (C5LR)

These statements reflect the profound changes that caring for a family member with COPD can bring to family life, highlighting the challenges in maintaining balance and cohesion within the family in a caregiving context.

SUB-THEME 4.3: FUTURE CONCERNS

The sub-theme of future concerns reflects the uncertainty and anxiety that caregivers of patients with COPD face regarding the progression of the disease and their ability to provide ongoing care. The prospects of worsening patient conditions, along with economic implications and the long-term sustainability of the caregiver role, generate deep fears, influencing psychological well-being and quality of life.

1. "I worry about the patient's condition worsening over time. I don't know how we will manage the growing needs and whether I will be able to maintain this level of care... I fear that I won't be able to ensure adequate assistance, especially if the disease progresses and requires more medical interventions or more intensive support." (C7AA)
2. "My main concern is what will happen if I get sick or need a break. I don't have a sufficient support network to cover my role as a caregiver... I worry about the emotional and physical future of the patient, but also my own. I don't know how we will handle the increasing burden and long-term challenges without adequate support and resources." (C2GS)
3. "I am anxious about the long-term financial implications. The costs associated with care and medical needs are already high, and I fear they will become unsustainable in the future." (C10DD)

These statements highlight caregivers' concerns about the future, shedding light on the uncertainty and anxieties related to disease progression, financial challenges, and the lack of support to address growing needs.

Discussion

This study aimed to explore the experiences of caregivers of patients with chronic obstructive pulmonary disease (COPD), the main difficulties encountered during their care, and the impact of these challenges on their quality of life in the six months following hospital discharge. The analysis of the experiences and difficulties of caregivers of patients with COPD highlights important insights into the challenges these individuals face and the implications for their quality of life. The results of this study add new insights into the existing literature on caregivers of COPD patients. Previous study (9) has explored the experience of COPD patient caregivers and the emotional, relational and practical burden , without focusing specifically on the period following hospital discharge. In contrast, the present study examines the experiences of caregivers during the first six months after patient discharge, a critical phase characterised by increased vulnerability, functional instability and limited support from health services (16). The results of our study highlight various critical aspects, including difficulties in daily management, emotional and psychological impact, and changes to family life. Regarding the difficulties in the daily management of the disease, caregivers report significant challenges in managing COPD on a daily basis, including issues with therapy administration and symptom management. These results align with previous studies that have documented how therapeutic complexities and symptom management can overwhelm caregivers (19-21). The statements from caregivers reflect a common sense of frustration and helplessness in the face of complex treatment regimens and the variability of patient symptoms. These aspects underscore the need to improve educational resources and training for caregivers, as indicated by studies suggesting targeted educational interventions to support disease management (3,22,23). The emotional and psychological impact emerges as a recurring theme in our study, with caregivers reporting high levels of stress and anxiety, along with a sense of exhaustion. The literature confirms that caregivers of patients with chronic illnesses such as COPD experience an increased emotional burden and a higher incidence of psychological disorders (8,9,2425). Our study highlights how the ongoing commitment to caregiving, worries about the future, and lack of adequate support can contribute to a decrease in the quality of life of caregivers. These results suggest the importance of providing psychological support and stress management programs for caregivers (1,9,10). Changes to family life are another significant theme that emerged. Caregivers report that caring for a patient with COPD has radically transformed their family life, limiting social activities and affecting family dynamics. These changes are supported by research demonstrating how caregiving can profoundly alter family routines and leisure time (26-29). Our study confirms that the restrictions imposed by caring for the patient can lead to family conflicts and a sense of isolation, highlighting the need for support strategies to maintain family balance. Difficulty in accessing resources and training has been a key concern for the caregivers interviewed. The lack of adequate training and useful resources has been documented in previous studies as a significant barrier to effective disease management (8,24,30,31). Caregivers often struggle with the correct use of medical equipment and understanding therapeutic instructions, highlighting the need for more accessible and personalized educational and training programs. Another theme that emerged was the ongoing support and relationship with healthcare professionals, considered fundamental aspects influencing the quality of life of caregivers. The results of our study show that regular communication and support from medical professionals are crucial for alleviating the burden on caregivers. However, the literature suggests that many caregivers experience insufficient communication and intermittent support (19,32,33. Improving communication and ensuring continuous support can contribute to more effective management and a reduction in the emotional and practical burden on caregivers. Finally, the future concerns expressed by caregivers reflect anxieties regarding the worsening of the patient's condition and the financial implications. These concerns are confirmed by studies highlighting how long-term caregiving can raise doubts about the sustainability of resources and the ability to face future challenges (33,34). Our study suggests that it is essential to provide structured support and adequate resources to prepare caregivers to manage long-term challenges. Furthermore, the literature highlights some experiences of interventions aimed at caregivers of patients with COPD; however, to date, these are limited and poorly structured. A recent systematic review identified twenty studies that include educational programmes, psychosocial support, and hospital-to-home transition interventions, but in most cases, these are patient-caregiver dyadic interventions, and only a few are designed specifically for caregivers. Furthermore, only a few studies have evaluated caregiver-centred outcomes, which were nevertheless positive (35) Evidence from other contexts, such as oncology, shows that interventions such as self-care support and psychosocial education can significantly improve caregiver preparedness (36). The discussion in the article clarifies how the daily difficulties of caregivers, their emotional experiences, and future concerns are closely interconnected and have significant implications for their quality of life. Understanding these aspects can inform the development of interventions and policies that improve support for caregivers and optimize the management of COPD.

Limitations of the study

This study, while providing important insights into the experiences of caregivers of patients with chronic obstructive pulmonary disease (COPD), has some limitations. The study was conducted only in Italian centers, whose practices and national culture could have affected the results. Although qualitative studies are not aimed at generalization, and strategies were adopted to ensure the transferability of findings, the replication of our findings in different sites or countries remains uncertain. Furthermore, the subjective nature of the interviews may lead to a partial representation of real experiences (29,37,38). Another limitation is that the study did not explore the unspoken needs of carers and did not collect concrete proposals for possible support interventions. Future studies could include a more in-depth assessment of unspoken needs and involve carers in the co-design of personalised interventions.

Relevance to clinical practice

The results of this study offer significant insights for improving clinical practice in the management of patients with COPD and supporting their caregivers. Caring for patients with COPD requires a multidimensional approach that considers not only the disease but also the well-being of caregivers, who play a crucial role in maintaining continuity of care and reducing exacerbations and hospital readmissions. An important element that emerged is the need to provide adequate training to caregivers, particularly regarding the management of therapy and symptoms. Many caregivers report difficulties in administering medications and using medical equipment, making it essential for the medical team to offer practical and personalized training at the time of the patient's discharge to ensure proper treatment adherence and improve clinical outcomes (3,9,24). Moreover, the emotional and psychological burden on caregivers cannot be underestimated. The study highlighted high levels of stress, anxiety, and a sense of overload—factors that can negatively affect the ability to provide adequate care. Therefore, it is crucial that clinical practice includes psychological support interventions for caregivers, including counseling services, support groups, and stress management techniques, to improve both the emotional well-being of caregivers and the quality of care provided to patients (26,28,39). Another relevant aspect that emerged is the importance of effective and regular communication between caregivers and healthcare professionals. Caregivers often report difficulties in understanding therapeutic instructions or receiving timely responses to their questions. Improving communication channels to ensure rapid access to physicians or nurses when needed is essential. Additionally, regular follow-up can help prevent exacerbations, identify problems early, and reduce readmission rates (23,29,39,40). Concerns about the long-term sustainability of the caregiver role are another central theme that emerged from the study. Planning for home support and access to financial resources in advance is crucial to alleviate such concerns, and it is essential for healthcare providers to consider these aspects, directing caregivers to social and welfare support services, thereby ensuring greater continuity of care (38,41. Finally, the difficulties faced by caregivers in managing daily activities and the changes imposed on family life demonstrate the need for a more holistic approach in the management of COPD. Integrating social and family support into clinical practice can reduce the caregiving burden on caregivers, improving their quality of life and that of patients (28).

Conclusions

This study aimed to explore the experiences of caregivers of patients with COPD, the main difficulties encountered during their care, and the impact of these challenges on their quality of life in the six months following hospital discharge. The themes and subthemes that emerged from the interviews provide a detailed and personal view of the caregivers' experiences, highlighting not only the practical and organizational challenges but also the profound emotional and relational implications of caring for a family member with COPD. The results underscore the complexities and daily difficulties, as well as the areas where increased support and training could make a significant difference. In light of these data, it can be stated that policies and clinical practices should be aimed at providing adequate training, psychological support, and improved ongoing communication to enable caregivers to face daily challenges and long-term concerns. Further research is needed to explore these areas more deeply and to develop evidence-based interventions that improve the well-being of caregivers and the overall quality of care.

Ethic Approval: The study was approved by the Intercompany Territorial Ethics Committee of the Maggiore della Carità University Hospital of Novara (protocol no. 12459, dated 12/05/2023; determination no. 708, dated 10/05/2023) and conducted in accordance with the Declaration of Helsinki

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