

Contributing to self-care of a person with chronic obstructive pulmonary disease: A qualitative study of the experiences of family caregivers

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Funding information

Centre of Excellence for Nursing Scholarship (CECRI), Rome, Italy, Grant/Award Number: 2.21.15

Abstract

Aim: To explore family caregivers' experiences of contributing to self-care of patients with chronic obstructive pulmonary disease (COPD).

Design: A qualitative description study.

Methods: Individual semi-structured interviews were conducted face-to-face, by telephone or video calls in a purposive sample of 17 family caregivers of patients with COPD recruited in Italy, and analysed through content analysis. The consolidated criteria for reporting qualitative studies (COREQ) checklist was used for study reporting.

Results: Ten subcategories were derived from 106 codes grouped into three main categories: family caregiver contributions to maintaining disease stable and ensuring a normal life for patients; family caregiver contributions to disease monitoring; and family caregiver contributions to coping with disease exacerbations. Family caregivers provided practical and emotional support, and their contribution was essential to improve treatment adherence, to enable the patient to continue living a normal life, and to have access to the healthcare services. Family caregivers were constantly vigilant and monitored patients daily to detect worsening conditions, and they managed exacerbations especially when patients were unable to do it due to their critical conditions.

Conclusion: This study broadens knowledge of family caregivers' contributions to patients' self-care in COPD, describing the different ways family members provide daily care to patients and the many responsibilities they take on.

Impact: Family caregivers perform a variety of behaviours when supporting patients with COPD in self-care, especially when patients are more dependent and the disease more severe. Nurses should acknowledge the various contributions provided by family caregivers and develop educational interventions aiming to support them in patient care and improve patient outcomes.

Patient or Public Contribution: Researchers shared the draft study report with participants for validation and feedback. This helped to strengthen the study design and results.

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KEYWORDS

chronic obstructive pulmonary disease, contribution, family caregivers, qualitative study, self-care, support

1 | INTRODUCTION

Chronic obstructive pulmonary disease (COPD) is a chronic degenerative disease characterized by physical symptoms such as dyspnoea, cough, sputum production and fatigue, and psychological manifestations including anxiety and depression (Global Initiative for Chronic Obstructive Lung Disease [GOLD], 2023). It represents the third cause of death worldwide and its prevalence increases with age and exposure to risk factors. COPD is responsible for a significant proportion of physician visits, emergency department access and hospitalizations (GOLD, 2023). The course of the disease is characterized by acute exacerbations—worsening of the patient's respiratory symptoms beyond normal day-to-day variations (Vestbo et al., 2013)—that lead to progressively deteriorating health, and losing autonomy in daily activities, especially in the presence of comorbidities and with ageing patients (Bendixen et al., 2014; Kim et al., 2012). Patients with chronic diseases need to perform daily self-care behaviours that are aimed at maintaining their physical and emotional stability (self-care maintenance) (e.g. following a specific diet; doing regular check-ups; performing activities to relieve stress); monitoring clinical manifestations of the disease (self-care monitoring) (e.g. checking daily body weight; monitoring phlegm colour) and managing clinical manifestations when they occur (self-care management) (e.g. modifying therapy to reduce symptoms; calling physician for guidance) (Riegel et al., 2012). As the disease progresses and autonomy decreases, patients affected by COPD need to rely on the help of informal caregivers (Grant et al., 2012; Nakken et al., 2015), who are any relative, partner, or close friend who has a significant personal relationship with, and provides a broad range of care for, a person with a chronic or disabled condition; they may live with the person receiving care or live separately from them (Family Caregiver Alliance, 2023). Usually, informal caregivers are family members, and for this reason, we used the term family caregivers throughout the article.

1.1 | Background

The support provided by family caregivers to patients with chronic diseases in performing self-care behaviours is defined as caregiver contribution to patient self-care. Family caregivers can contribute to chronically ill patients' self-care by recommending (or substituting for) them to perform behaviours aimed at maintaining the patient disease stability (e.g. encouraging them to follow a healthy diet, making appointments for checkups on behalf of the patient) (caregiver contribution to self-care maintenance), by facilitating the monitoring and perception of symptoms (e.g. watching for increase in patient breathlessness or weight) (caregiver contribution to self-care monitoring), and by responding to signs and symptoms of an exacerbation (e.g. administering or recommending patient to take an extra dose of medication to treat symptoms) (caregiver contribution to self-care management) (Vellone et al., 2019). Even when

family caregivers perform behaviours on behalf of the patients, especially when older or in an advanced stage of the disease, those behaviours are considered contributions to patient self-care as they are aimed at the care of the patients (Vellone et al., 2019). Family caregiver contribution to patient self-care has been described in several chronic conditions, such as heart failure (Durante et al., 2019; Wilson et al., 2022), ostomy (Giordano et al., 2022) and in multimorbidity (Iovino et al., 2021), but, to our knowledge, has not yet been investigated in COPD.

Research on family caregivers of patients with COPD has mostly focused on the caregiver's psychological needs, or the burden of caregiving and its negative effects on caregivers' physical and psychological health (Cruz et al., 2017; Giacomini et al., 2012). Moreover, the qualitative studies carried out up until now to explore the experiences of family caregivers of patients with COPD mainly addressed the influence of caregiving on family caregivers' lives, even though some information about what family caregivers do daily to support patients in their self-care is reported (Andersen et al., 2017; Bove et al., 2016; Hynes et al., 2012; Strang et al., 2018). One thematic synthesis identified several possible contributions to the self-care of patients with COPD through a secondary analysis of qualitative studies conducted to explore the experiences of family caregivers of COPD patients (Matarese et al., 2021). No qualitative study has specifically investigated family caregivers' experiences of contributing to patient self-care in COPD and what behaviours they engage in when taking responsibility for supporting patients in their self-care. Knowledge derived from this study could help nurses identify which care behaviours are carried out daily by family caregivers to support patients with COPD in managing their disease, which family caregiver contributions help to manage the patient's disease, which ones they struggle more with, and which ones should be addressed in educational programmes to support family caregivers in their caregiving role.

2 | THE STUDY

2.1 | Aim

This study aimed to explore the experiences of family caregivers in contributing to the self-care of patients with COPD.

2.2 | Design

A qualitative description design was used, as described by Sandelowski (2000). This design provides a direct description and complete summary of the phenomenon under study, using the language of participants and remaining close to the data (Sandelowski, 2000). The quality of the study reporting was assured by using the consolidated criteria for reporting qualitative studies (COREQ) checklist (Tong et al., 2007) (see Table S1).

2.3 | Sample/participants

A purposive sample of family caregivers of people with COPD was recruited in a pulmonology clinic and hospital unit in northern Italy, to select participants who had knowledge and experience of the phenomenon under study (Morse & Field, 1996). Inclusion criteria were as follows: being 18 years or older, being a family caregiver of a patient who had been diagnosed with moderate, severe, or very severe COPD for at least 3 months, and being willing to sign the informed consent form. The COPD stages were based on the Global initiative for chronic Obstructive Lung Disease (GOLD) classification of the severity of air-flow limitation, measured through the spirometry values of forced expiratory volume at 1s (FEV1) after administration of bronchodilator. GOLD classifies the disease as mild (or GOLD 1) $FEV1 \geq 80\%$, moderate (or GOLD 2) $50\% \leq FEV1 < 80\%$, severe (or GOLD 3) $30\% \leq FEV1 < 50\%$ and very severe (or GOLD 4) $FEV1 < 30\%$ (GOLD, 2022). We selected family caregivers of patients with moderate to very severe COPD since patients usually need greater support to manage the disease in these stages. Caregivers were excluded if they were caring for a patient at GOLD 1 stage, or in the presence of a diagnosis of severe cognitive impairment. To ensure a broad range of experiences, we planned to include male and female participants of different ages, education levels, economic conditions, family relationships with patients (i.e. children, partners/spouses, siblings), taking care of patients in different stages of the disease, and for different amounts of time.

2.4 | Data collection

In the days established for recruitment, two research assistants checked the clinical records of the pulmonology clinic or hospital unit to see which of the patients listed for a visit or admitted had had a diagnosis of moderate, severe or very severe COPD for at least 3 months, and they approached the family caregivers who were with the patients in the healthcare settings and informed them about the study aim. If they were interested in participation, they were asked to sign the informed

consent form. Next, they were contacted by the research assistants via telephone or email to make an appointment for the interview, which could be conducted by telephone, video call or face-to-face depending on their preferences. Family caregivers' demographic and patients' clinical data were gathered using a questionnaire administered by telephone or in person. Semi-structured interviews were used to collect qualitative data. One interview was conducted for each participant. The interviews were conducted by two female research assistants (RP, GP) trained in qualitative interview methods, one engaged on a PhD programme and the other on a bachelor in nursing, and the study was part of their dissertation work. No participant was known by research assistants except for one who was a nurse working in the same healthcare setting as one of the research assistants. The interviews were carried out with no other person present, to allow free narration. An interview guide was developed based on researchers' experiences and literature on the topic, and included a general opening question, questions encouraging participants to report their experiences, and a summary question, as described in Table 1. The questions were tested on the first two participants and no changes were needed as they were well understood by participants and permitted the reporting of their experiences. Data were collected until saturation was reached (Kerr et al., 2010). The saturation grid is reported in Table S2. The interviews were audio recorded and transcribed verbatim.

2.5 | Ethical consideration

The study was carried out in accordance with the Declaration of Helsinki. The Ethics Committee of a healthcare institution approved the study (no. 15348; 04/26/2021). Participants were informed about the study aim and procedures, and if they agreed to participate, they signed a written consent form. The patients' demographic and clinical data were obtained from family caregivers who consented to provide such information. Anonymity was guaranteed by using alphanumeric codes (from C1 to C17) to identify participants in the transcripts, data analysis and in the study report.

TABLE 1 Interview guide.

General opening question	Think about a typical day, can you tell me what you usually do to take care of your family member with COPD?
Probing questions	Do you know what medicines your family member takes? Do you help your family member to follow the medicine prescriptions? Do you know what disease symptoms you need to check for in COPD? What do you do to prevent the symptoms worsening in your family member? How do you check the disease symptoms (i.e. breathlessness, cough)? Can you tell me what you do when your family member has symptoms? Who do you contact to receive information, advice and support? Have you accessed any social or healthcare service? Have you requested any form of economic support? What else would you need to help your family member better?
Summary question	Would you like to tell me more about your experience of taking care of your family member?

2.6 | Data analysis

The data were analysed and interpreted using inductive content analysis (Graneheim & Lundman, 2004). A four-step process was followed. First, transcripts were read several times to acquire a sense of the whole. Second, codes were generated by reading the transcripts word by word. Third, codes were grouped into subcategories based on their similarities and differences. Fourth, the subcategories were organized into main categories based on their commonalities. Two researchers (RP and MM) independently coded and categorized the data. The codes, subcategories and main categories developed by researchers were compared, and any difference was resolved through discussion. A third researcher (BA) analysed the codes and categories for consistency, and any discrepancy was resolved through discussion. The transcripts were exported into the software Atlas.ti Windows, Version 22.0.6.0 (Atlas.ti, 2022) to facilitate data management and coding.

2.7 | Rigour

To ensure trustworthiness, criteria for credibility, confirmability, dependability and transferability were considered (Graneheim & Lundman, 2004). Study credibility was assured by prolonged data engagement, independent data analysis and peer debriefing. Confirmability and dependability were guaranteed by keeping an audit trail during the whole study process, supervised by a member of the team not involved in data analysis. Member checking was carried out by contacting five participants by telephone, who confirmed that the findings reflected their experiences. Transferability was confirmed by providing sufficient details regarding the study participants, the context where the research was carried out, and a thick and rich description of the research process and findings.

3 | FINDINGS

3.1 | Characteristics of participants

Seventeen family caregivers of patients with COPD were identified, none of whom refused to participate in the study. The mean age of caregivers was 63 years, and of patients 75. Family caregivers were mainly females (58.8%) and spouses/partners or children (88.2%) of patients. Most were caring for patients in advanced COPD stages (Table 2).

Eleven interviews were carried out by telephone, five face-to-face at the healthcare setting and one via video call, according to participant preferences. The interviews lasted from 10 to 63 min, with a mean duration of 27 min.

3.2 | Description of categories

A total of 106 codes were derived from the transcripts and grouped into 10 subcategories, which were clustered into three main categories that describe the family caregivers' experience of taking care of a patient with COPD: (1) family caregiver contributions to maintaining disease stable and ensuring a normal life for patients; (2) family caregiver contributions to disease monitoring and (3) family caregiver contributions to coping with disease exacerbations. The codes, subcategories and main categories are summarized in Table 3.

3.2.1 | Family caregiver contributions to maintaining disease stable and ensuring a normal life for patients

This category, derived from seven subcategories, describes the daily behaviours and strategies adopted by family caregivers to prevent respiratory infections, promote the patients' physical and psychological health, and help patients to continue leading a normal life.

Contributions in preventing respiratory infections

Family caregivers reported performing several behaviours to prevent patient respiratory infections and disease worsening. Non-cohabitant family caregivers reported making daily visits to their relatives to check their health status, keep them company and make them feel cared for, as reported by a son:

In the morning I go to my mum's, I check that the oxygen tank is fine, that everything's in order, then I go to work. When I get home from work, I stop by my mum's for a moment and see if everything is still fine.
(C11)

Some family caregivers believed it important to avoid contact with people with colds and flu, and to ensure the quality of the air and the environment where the patient lived, for example, by eliminating draughts, checking room humidity and temperature, and cleaning the air-conditioning filters, as reported by a caregiver:

We check that the air circulation is not harmful, for example that there are no drafts. We check that there is a suitable temperature for her disease; that is, not above 30°C, and it should not drop below 18°C, neither too hot nor too cold. A good temperature is around 19/20°C, both in winter and in summer.
(C12)

They also reported that they regularly cleaned the oxygen therapy and nebulizer devices. Family caregivers recognized the importance of smoking cessation for the patients, and they gave up smoking themselves or avoided smoking in the presence of patients to help them quit:

TABLE 2 Characteristics of participants (family caregivers $n = 17$).

Characteristics	Caregiver	Patient
	Mean (SD) (range)	Mean (SD) (range)
Age	63.29 (10.20) (46–78)	75.29 (9.17) (58–89)
Years from COPD diagnosis		8.06 (6.21) (1–25)
Caregiving hours/week	59.88 (72.38) (0–168)	
Caregiving years	7.82 (6.45) (1–25)	
	<i>n</i> (%)	<i>n</i> (%)
Gender		
Female	10 (58.8)	10 (58.8)
Male	7 (41.2)	7 (41.2)
Gender combination between caregiver and patient		
Male _c and male _p	1 (5.9)	
Female _c and female _p	4 (23.5)	
Female _c and male _p	6 (35.3)	
Male _c and female _p	6 (35.3)	
Relations with patients		
Children	7 (41.1)	
Spouse/partner	8 (47.1)	
Brother/sister	2 (11.8)	
Cohabitants		
Yes	9 (52.9)	
Marital status		
Unmarried	2 (11.8)	
Married	14 (82.7)	
Divorced	1 (5.9)	
Education		
Middle school	7 (41.1)	
High school	8 (47.1)	
University degree	2 (11.8)	
Perceived income adequacy		
More than necessary	3 (17.6)	
Sufficient for living	12 (70.6)	
Less than necessary	2 (11.8)	
Patient COPD stage		
GOLD 2	3 (17.6)	
GOLD 3	4 (23.5)	
GOLD 4	10 (58.8)	
Setting of recruitment		
Clinics	16 (94.1)	
Hospital units	1 (5.9)	

Abbreviations: c, caregiver; COPD, chronic obstructive pulmonary disease; p, patient; GOLD, global initiative for chronic obstructive lung disease; SD, standard deviation.

He used to smoke, but not now; since he last came back from the hospital, no one smokes in the house anymore. I go outside [to smoke] and the only thing is that then he grumbles.

(C4)

Some patients struggled to quit smoking, and family caregivers recognized that the addiction was not easy to overcome. Despite the awareness of the consequences of smoking, a family caregiver reported providing cigarettes to the mother affected by COPD:

My mum still smokes. So, I would like [her to stop smoking] but she can't; unfortunately, I'm also an accomplice because it's me who, together with her cousin, buys her the packets of cigarettes.

(C16)

Some family caregivers reported teaching patients breathing techniques that they learnt when attending yoga classes, to improve their breathing. Finally, family caregivers reported they booked visits and accompanied patients to visits to the patients' general practitioners (GPs) and specialists.

Contributions in promoting patient's healthy lifestyle and normal life

Family caregivers performed several behaviours to ensure patients received good nutrition, prevent falls, and promote patients' mobility. Family caregivers knew that nutrition was important for maintaining health and checked that patients ate adequately, by shopping for groceries themselves and providing nutritious, healthy foods:

She said she ate but I think she also neglected nutrition during the pandemic, which is still an aspect that I must constantly follow.

(C16)

They also stimulated their loved ones to keep moving and not lead a sedentary life:

I always have to encourage her to take a walk because she is always sitting.

(C11)

Since most patients were older, with mobility impairments, and/or using walking aids and oxygen therapy equipment, family caregivers were also particularly attentive to the prevention of accidental falls at home:

Anyway, I'm always behind her because I'm afraid that she might fall. I'm afraid she will trip over the line [oxygen extension cord].

(C3)

TABLE 3 Codes, subcategories and categories derived from transcripts.

Subcategories	N codes	Codes
Category 1. Family caregiver contributions to maintaining disease stable and ensuring a normal life for patients		
1. Contributions in preventing respiratory infections	11	Accompanying to medical visits Avoiding smoking near patient Cleaning small volume nebulizer Cleaning the oxygen therapy devices Controlling the environment Making daily visits to patient Organizing patient's checkups Preventing pulmonary infections Persuading stopping smoking Stopping smoking Teaching breathing exercises
2. Contributions in promoting patient healthy lifestyle and normal life	8	Assuring proper diet Checking nutrition Supervising physical activity Preventing falls Stimulating mobility Accompanying for a walk Stimulating to maintain a normal life Stimulating to maintain the family role
3. Supporting adherence to treatment	17	Administering medications Checking oxygen prescription adherence Checking adherence to small volume nebulizer Checking small volume nebulizer prescription adherence Going to physician for prescriptions Managing oxygen devices Preparing breath stimulator Preparing medications Preparing oxygen therapy devices Preparing small volume nebulizer Providing a written schedule of prescribed medications Providing a dosette box Refilling medications Refilling oxygen in the stroller Regulating oxygen therapy level Reminding to follow the prescribed regime Supervising medicine intake
4. Contributions in basic and instrumental activities of daily living	11	Accompanying to the bathroom Carrying out household chores Doing laundry Doing shopping Driving to hairdresser Helping in dressing Helping in personal hygiene Helping to move with the oxygen cylinder Helping with eating Ironing clothes Preparing meals
5. Contributions in providing emotional support and acquiring knowledge about the disease	12	Checking emotional state Offering emotional care Being informed about disease Being informed about medications Knowing how to use oxygen cylinder Knowing signs and symptoms of exacerbation Knowing the side-effects of medications Lack of information about medications Lack of information about the disease Learning by experience Need for information Searching for information about the disease

TABLE 3 (Continued)

Subcategories	N codes	Codes
6. Contributions in navigating the healthcare system and communicating with healthcare providers	14	Addressing fragmentation of care Contacting oxygen delivery services Managing administrative procedures Managing therapeutic prescription plan Searching for appropriate services Managing discordance among HCPs Maintaining relationship with HCPs Not receiving support from GP Not receiving support from HCPs Receiving support from clinics Receiving support from GP Receiving support from HCPs Receiving support from home care services Receiving support from social care services
Category 2. Family caregiver contributions to disease monitoring		
1. Contributions in checking for signs and symptoms of the disease and emotional distress	17	Difficulty in interpreting symptoms Monitoring blood oxygen level Monitoring breath sounds Monitoring changes in patient's voice Monitoring cognitive status Monitoring cough Monitoring drowsiness Monitoring fever Monitoring level of energy Monitoring loss of appetite Monitoring sputum Monitoring symptoms during the night Monitoring worsening of the disease Monitoring vital signs Setting an alarm call system Monitoring anxiety Monitoring depression
2. Contributions in checking for side-effects of treatment	3	Monitoring medication allergy Monitoring hypercapnia Monitoring skin integrity
Category 3. Family caregiver contributions to coping with disease exacerbations		
1. Contributions to dealing with physical and emotional symptoms of exacerbation	10	Deciding about the appropriate healthcare service Deciding to go to ER Deciding what doctor to contact Managing cough Managing dyspnoea Managing increased sputum or change of colour Recognizing symptoms of exacerbation Managing anxiety Managing depression Learning to manage exacerbations
2. Contributions to dealing with patient's other health problems	3	Dressing wounds Managing comorbidities Handling urinary incontinence

Abbreviations: ER, emergency room; GP, general practitioner; HCP, healthcare provider.

Family caregivers reported that they stimulate patients to continue leading a normal life and fulfil their usual family role despite the limitations due to the disease. A husband reported:

So, I make sure that she wakes up around 9–9:30 in the morning and that she behaves normally during the

day, making the beds and cooking. Let's say, I try to make her complete the day as a wife, with a husband and children in short.

(C8)

A wife added:

If it is a nice day, I take him shopping with me. If it's spring or summer, I put him in the wheelchair or in the car and take him for a ride.

(C7)

Supporting adherence to treatment

Family caregiver behaviours were also aimed at ensuring that patients followed the medical regime as prescribed. Several medications were prescribed to COPD patients, delivered through inhalers, small volume nebulizers, pills, a combination of these, and by cylinder, stroller, or tank in the case of oxygen therapy. Caregivers reported that they played an active role in the intake of patients' daily medications, or just offered supervision or reminders. Several strategies to improve adherence were used by family caregivers, such as organizing the pills in a dosette box, providing a written schedule, or administering them directly to patients. They also managed the medication prescriptions at the doctor's office and pharmacy, and the replacement of the oxygen cylinder or the refilling of the oxygen stroller when needed. Moreover, they learnt how to use inhalers and oxygen therapy devices, checked correct administration, and encouraged patients to use them as prescribed:

Oxygen must be used at 1L/min. But sometimes she doesn't use it. She turns 87 this year and managing older people is difficult, they see things their own way. This morning I also insisted that the physician should scold her, because lately she was moving around the house without oxygen. I came into the house a couple of times, and both times she was without oxygen, so I scolded her.

(C10)

A few family caregivers reported that medications were managed completely by the patients without their involvement, although they were aware of the prescribed medicines:

For now, he is still quite independent in taking medicines. I'm careful though because every time I take him to the hospital, they tell us "He's making mistakes in taking his medicines", but it doesn't seem true to me, but I'm careful.

(C13)

Contributions in basic and instrumental activities of daily living

Family caregiver behaviours helped patients to carry out the activities of daily living when they were not able to do them independently. They reported helping them with dressing, using the bathroom, and personal hygiene, according to patient capabilities, and drove them to the hairdresser when needed:

She is still quite autonomous in everyday activities, and in daily personal hygiene; but if she has to take a shower or wash her hair, she needs help. We concentrate these activities above all on the weekend; if she has to go to the hairdresser, we will accompany her.

(C2)

Family caregivers by themselves or with the help of paid assistants performed the household chores, such as doing laundry, ironing, preparing meals, cleaning the house or doing shopping, since patients often were not able to do these chores due to breathlessness, fatigue or the presence of oxygen therapy devices:

I'm scared, I'm scared of that [oxygen] tank over there. Because she goes to the bathroom, she goes where she goes, and you always have to push it. I push it because it's heavy, she couldn't. You can do it when it starts to be almost empty.

(C3)

They had to overcome patients' resistance in accepting help from others, and found alternative solutions to support patients in daily activities:

We applied for meals on wheels, but mum refused them, they were not welcome. She's suspicious, and they weren't considered good, so she said no. So, we get by with something family members cook or something ready-made from butchers or delis and so on.

(C16)

Contributions in providing emotional support and acquiring knowledge about the disease

Family caregivers described the emotional support provided to prevent patients' emotional distress due to the limitations imposed by the disease on patients' personal and social life. Often, patients did not want to leave the house due to the presence of respiratory aids and mobility impairment. Family members made them feel their closeness and helped them cope with the disease and its limitations:

It is precisely the mood that tends to go down and therefore in the end my greatest commitment, which has recently increased, is precisely that of setting aside a part of the day for her, based on work commitments, and stopping by for a visit and to keep her company.

(C1)

This subcategory also includes family caregiver experiences of acquiring disease-related knowledge, learning how to deal with the disease and prevent exacerbations. Some of them reported being fully informed about the patient's medications, signs and symptoms of the disease, and the side effects of medications, including hypercapnia in cases of high levels of oxygen therapy:

A blast of air is enough to trigger a flare-up and then antibiotics are needed which debilitate you even more, because the various inhalers, antihistamines, nebulizers, and oxygen therapy are sometimes not enough and you also have to resort to drugs such as antibiotics or cortisone, which debilitate the person. Cortisone takes calcium away from the bones and antibiotics weaken you physically, but also at intestinal level.

(C12)

Some other family caregivers reported knowing very little about the disease, especially when it was fully managed by the patients. Some of them complained that healthcare providers (HCPs) provided them with very little information about the disease, and they needed to get information from other sources. They often learnt how to manage the disease from their daily experiences, and sometimes from their mistakes, as reported by a wife:

We have learned over the years because it was difficult at first. In fact, in the beginning, when they gave us the inhaler, I forgot more than once, because first he took the pills or did the aerosol therapy. He has to use the inhaler twice in the morning and twice in the evening, but at the beginning I did it four times in one administration because no one had ever explained it to me. When he was hospitalized for about a month (...) we discovered that it wasn't four deliveries at a time, but two.

(C6)

Contributions in navigating the healthcare system and communicating with healthcare providers

This subcategory includes family caregivers' experiences of using the National Healthcare System to obtain the services needed for patient care and maintain a relationship with patient healthcare providers. Although several healthcare services were available for COPD patients, caregivers reported that at the beginning they struggled to understand which services they could access, which service to contact at a regional and local level and which specialist was the best based on the patient's condition, as reported by a daughter:

Initially we felt a bit thrown about, because we had to look for a pulmonologist, but without any directives. At the beginning we had been directed to a service for possible surgery; we managed to make the visit

on February 10 [2020] and we got the answer in September and learned that she couldn't have the operation as her COPD was already too severe. Before orienting ourselves and being followed in pulmonology, it took some time and it happened by chance, by having a private visit with Dr. X, and then the taking charge started. But I think that if you don't take the right path, and you don't have any indication to follow, you must fend for yourself a bit.

(C1)

When the patients suffered from multiple chronic conditions, as often occurred in older patients with COPD, family caregivers were responsible for the integration of care between the various specialists, as each physician only considered one particular health problem, as reported by a wife:

There is this fragmentation that always disorients me. In the sense that the pulmonologist only treats the lungs and respiratory problems, the rest does not concern them, the cardiologist too. No one gives me information relating to the person, rather than the symptoms, the disease. I'm groping in the dark.

(C9)

The problem of care fragmentation was also reported within the same service at clinics, where patients were not entrusted to a specific specialist or nurse but saw different HCPs at each visit:

You don't always have the same physician [at the COPD clinic], there are 5/6 physicians who rotate. When they book you for a visit, you see a physician at random. My mum is attached to a couple of them, but we can't find them all the time. They told us that there isn't the possibility of requesting a visit with a particular physician. (...) For example, this morning there wasn't the usual nurse doing her blood gas analysis and she asked for the usual one. Actually, I too, who am used to accompanying her, have preferences.

(C10)

Some family caregivers did not have a real understanding of the functioning of the home care services due to the presence of multiple service providers and the turnover of home care personnel:

Now, a new social worker will come because the other one has gone on vacation and she'll come with another nurse who's managing the case and she'll ask me what's going well or badly, if she's feeling better, or how she's feeling. She's not the one from the integrated home care service. Is she perhaps the family nurse?

(C3)

According to Italian law, the treatment plan had to be renewed periodically and family caregivers had to learn the administrative procedure for obtaining free medicines:

You also must get by a bit even with the management of the medication, you must know that you need to renew a therapeutic plan and all this bureaucratic stuff that unfortunately you only know if someone tells you, guides you, and that guidance isn't there. Well, until you find the right path, if you get guided then everything works, but at the beginning you work a bit blindly.

(C1)

Family caregivers managed the communication with the HCPs in charge of the patient's health problems either together with the patients or autonomously. Some caregivers reported feeling supported by the GP with whom they established a trusting relationship and who was always available when a health problem occurred, as a daughter reported:

We have a physician who is very present, and he was so also in the only adverse event that happened to us. I send him just a message on the phone and he answers me promptly, he gives me directions, he reassures me, so that I can carry it out with my mother. Well, we are quite well followed up, reassured by the general practitioner.

(C1)

Family caregivers also reported receiving support from other health-care professionals such as pulmonologists or home care workers:

Well, we have a good relationship with the physiotherapist. In this pandemic period, since we were unable to do rehabilitation at the center, we've accessed the physiotherapist home service at least twice a year. She has already done three cycles since she got worse in January last year. We are lucky because the nursing home that managed the service always sends us the same physiotherapist.

(C1)

Other family caregivers, on the other hand, failed to establish a trusting relationship with the patient's GP, especially when the old GP retired and a new one took over, breaking the long mutual connection:

The previous practitioner referred her to a specialist, and the specialist prescribed aerosols or antibiotics. This new one never even felt her lungs, examined her in general, and never sent her to a pulmonologist.

(C3)

They complained about the lack of support, especially on Sundays when the services were not guaranteed, often forcing them to go to the emergency room (ER):

The GP we had before retired. Now, unfortunately, I can't find support in the practitioner we had to choose, rather I take him [the patient] to the emergency room, because he [the GP] doesn't give me any confidence.

(C4)

3.2.2 | Family caregiver contributions to disease monitoring

This category, derived from two subcategories, describes the behaviours and strategies that family caregivers adopted daily to monitor the physical and emotional manifestations of the disease and the side effects of medications.

Contributions in checking for signs and symptoms of the disease and emotional distress

Family caregiver behaviours were directed to monitoring clinical and psychological manifestations of the disease. They reported checking increased phlegm and dyspnoea, phlegm colour changes, decreased energy levels and asthenia, oxygen levels through the oximeter, voice changes, drowsiness and cognitive decline:

I keep her monitored especially when the oxygen therapy dosage is changed, in this case I also check her several times a day to see if she's okay.

(C2)

This monitoring was also carried out at night by cohabiting caregivers by using remote communication devices:

During the night, if she needs me, she calls me on my cell-phone because otherwise I don't hear her, our rooms are nearby, but I keep the television on, and even with the volume low, I can't hear her, so we use the cellphone.

(C3)

Living daily with the patients helped family caregivers to become familiar with what the clinical changes were and how to interpret subtle symptoms:

I see it from his breathing, how he breathes, how he moves. But nobody told me. We don't have a direct relationship with the physician who is treating my husband, so she didn't tell me what to watch out for. I do it by instinct and as I'm used to doing when I care

for a person who is sick. So, I see it from his breathing, from his mood, from how he responds to me, if he is predisposed towards others. But I don't have other physiological data to find out how to act.

(C9)

Family caregivers acknowledged difficulty in interpreting COPD symptoms when occurring, especially when patients did not complain about them, or they were similar to those of other chronic diseases:

Unfortunately, her illness sometimes doesn't give a signal, in the sense that she really gets out of breath, and she gets this breathlessness, but she doesn't cough; therefore, let's say that it doesn't give us a warning, a sign of worsening, as it can be like a flu or like a cold, and right away the wheezing and shortness of breath arise.

(C1)

Family caregiver behaviours were also directed at monitoring emotional distress, such as depression and anxiety, which are frequently associated with the disease and its exacerbations. Monitoring anxiety and depression was considered important for family caregivers as they influenced patients' motivation to take care of themselves and manage their disease:

Those who have had a chronic illness for years go into depression because they lose their autonomy, they must always depend on others for help. Because if human beings don't have their autonomy they go into psychological decline.

(C12)

Contributions in checking for side-effects of treatment

As the treatments for COPD, including oxygen therapy, could cause several side-effects, family caregivers contributed to checking for their appearance. A caregiver reported constantly checking for symptoms of hypercapnia:

Mum has the problem of hypercapnia, so we can't exaggerate with oxygen, because then the problem is that she retains carbon dioxide, there's no exchange and she gets intoxicated, poor her. But we make sure that she doesn't feel drowsy and that she's awake, and, luckily, we can notice that and honestly it has rarely happened to us.

(C2)

Moreover, family caregivers reported looking for the occurrence of medication allergy (C3) and the effects of medication on skin integrity (C12).

3.2.3 | Family caregiver contributions to coping with disease exacerbations

The category, derived from two subcategories, describes the behaviours performed by caregivers to deal with COPD exacerbations, and the symptoms of other chronic conditions from which older patients often suffer.

Contributions to dealing with physical and emotional symptoms of exacerbation

This subcategory includes behaviours performed and decisions made by family caregivers to recognize and manage exacerbations. In the case of flare-ups, they reported that it was their responsibility to decide what to do on behalf of the patient; for example, to reduce the symptoms they regulated the oxygen level, administered an extra dose of inhalers, antibiotics or aerosol therapy. They could also decide to call the GP or take their family member to the ER, especially when the GP was not available:

We went straight to the ER because in that moment she just couldn't breathe. Mum used oxygen only at night, while that morning there, practically, she just couldn't breathe.

(C1)

Sometimes family caregivers had to make decisions about hospitalization while overcoming patient resistance:

I realized that something had changed, that she was physically wasting away and so I insisted that she get checked. And not only that, I insisted that she did pulmonary rehabilitation. Rehabilitation had already been offered to her on several occasions, but she had always refused it. At that moment I made a point of telling her that she could no longer afford to refuse it. We had a moment of crisis because she got angry because I decided to have her hospitalized for rehabilitation and she didn't want to accept it.

(C1)

Exacerbation management is complicated by the rapid onset of dyspnoea and by family caregivers' difficulty in interpreting symptoms, especially in case of multiple chronic conditions:

We are always uncertain whether to have her seen first by the cardiologist or the pulmonologist. And this is a bit difficult to handle.

(C2)

Family caregivers learned to manage the anxiety that accompanies the disease and breathlessness by administering anxiolytics (C17), suggesting breathing exercises or calming patients down by speaking in a calm tone (C9).

Contributions to dealing with patients' other health problems

Family caregivers reported that patients with COPD were affected by other chronic conditions, such as heart failure, diabetes, kidney failure, stroke or tumours, and they also supported them in dealing with such problems. The coexistence of other health problems made it difficult for family caregivers to manage patients' health.

She also has another disease that is difficult to manage, which is heart failure, the management of which involves us a lot because you must always balance what she drinks with what she urinates, if she gains weight because she retains fluids, we never know if she's not breathing because she's full of fluids or because of the COPD.

(C2)

4 | DISCUSSION

The aim of this study was to explore the experiences of family caregivers in contributing to the self-care of patients with COPD. We found that family caregivers contributed in several ways, highlighting their crucial role in the COPD management. Family caregiver contributions were aimed at preventing patients' exacerbations and promoting a normal life, checking for the occurrence of symptoms or treatment side effects, and dealing with them and those of other chronic conditions when needed. The caregiver contributions identified in our study are consistent with the three dimensions described by the Situation-Specific Theory of Caregiver Contributions to Heart Failure Self-Care (caregiver contributions to self-care maintenance, to symptom monitoring and perception, and to self-care management (Vellone et al., 2019), which were also identified in a previous study (Matarese et al., 2021). Therefore, our findings reinforce the evidence that caregiver contributions to the self-care of patients with chronic diseases concern these three dimensions. Previous studies identified a few activities that family caregivers can perform to support patients with COPD (Bryant et al., 2016; Gautun et al., 2012; Marques et al., 2021). In our study, we identified a wider spectrum of contributions of family caregivers, and they ranged from emotional to practical support, from providing information to patients to communicating with HCPs, from symptom recognition to symptom management, from ensuring access to the healthcare services to applying for economic help. The fact that family caregivers were mostly cohabitants with patients or, when not cohabiting, made daily visits to patients, may have contributed to generating this large number of experiences.

4.1 | Family caregiver contributions to maintaining the disease stable and ensuring a normal life for patients

We found that family caregivers performed numerous behaviours to contribute to patient self-care maintenance, and these behaviours were directed at preventing respiratory discomfort and emotional distress,

supporting treatment adherence, collaborating with HCPs, gaining knowledge of COPD, helping patients to access healthcare services, helping them in daily activities, and in ensuring that they could lead a normal life. Only a few of these contributions were identified in previous studies (Bryant et al., 2016; Gatti et al., 2018). Our findings show that family caregivers put considerable efforts into ensuring access of patients to the best care offered by the national health system. Regardless of the healthcare systems, worldwide the access to care and to economic benefits for patients with chronic diseases often requires dealing with many administrative procedures that can be time-consuming and difficult to follow for both patients and family caregivers (Strang et al., 2018). The efforts involved in navigating the healthcare systems can increase the burden of family caregivers of patients with COPD (Crawford et al., 2013; Lippiett et al., 2019). Healthcare systems should organize their services to facilitate communication and effective integration between health and social services, and not leave to the caregivers and patients the burden of the integration of services and treatments.

Our study confirms that some family caregivers do not feel supported by healthcare professionals in their caregiving role. Family caregivers are not recognized as collaborators and allies in the patient's care, and little attention is paid to informing and educating them. Studies have demonstrated that family caregivers have limited knowledge about COPD (Matarese et al., 2023; Raptis et al., 2021). Increasing caregiver knowledge could lead, on one hand, to increasing the knowledge of patients with COPD, as there is evidence that the knowledge levels of patients and their caregivers are interrelated (Matarese et al., 2023); and, on other hand, to better care when family caregivers need to act on the patient's behalf. When a patient is followed by several health providers and services, such as GPs and pulmonologists, pulmonary and oxygen therapy clinics, and home care services, information may be fragmentary, tied to the specific purpose of the service and considered as already being provided by other health professionals. In our study, family caregivers reported that they often had to learn to manage the patient's disease by trial and error. Although some studies have demonstrated the positive effects of their involvement in educational programmes (Vagharseyyedin et al., 2022), family caregivers are still rarely included in such programmes and even when they are, they have not been specifically designed to support family caregivers (Marques et al., 2021; Vagharseyyedin et al., 2022).

Literature has found that family caregivers' support contributes to improving patients' medication adherence (Trivedi et al., 2012), for example, by helping to remember, prepare and buy medications (Duarte-de-Araújo et al., 2018; Trivedi et al., 2012); to promoting tobacco smoking cessation (Trivedi et al., 2012); to improving patients' dietary habits (Prarach & Ua-Kit, 2023); and to increasing patient participation in pulmonary rehabilitation programmes (Chen et al., 2017).

4.2 | Family caregiver contributions to disease monitoring

Family caregivers play an important role in helping patients with COPD detect early clues of disease worsening. In our study, we

found that they identified changes by watching the patients or asking patients how they felt, and this monitoring process was favoured by cohabitation with the patient, or by the caregiver visiting daily. Due to the subjective nature of symptoms, patients and family caregivers use different clues to detect the occurrence of clinical manifestations of the disease: the patient can perceive subjective symptoms (e.g. fatigue, breathlessness, chest pain) and the caregiver can monitor objective signs (e.g. changes in oxygen saturation) or observe their consequences on the patient (e.g. limitation in physical activity due to fatigue) (De Maria et al., 2022). These contributions to patient self-care monitoring have been little studied in COPD, whereas they have been more extensively addressed in other chronic conditions, such as congestive heart failure (Macdonald et al., 2013).

4.3 | Family caregiver contributions to coping with disease exacerbations

In our study, family caregivers reported supporting patients in handling medical equipment, such as oxygen cylinder and nebulizers, taking medications, and deciding which healthcare service or provider to contact to solve health problems. Family caregiver contributions are important during acute exacerbations, since patients have difficulties in following the prescribed treatment and making decisions for their health (Suresh et al., 2022), and when patients suffer from other chronic conditions and several treatments need to be followed (Doos et al., 2015). The family caregiver also contributes to reducing and treating the patient's psychological distress caused by suffering from a disabling disease and breathlessness. HCPs often prioritize physical symptoms and medication management, leaving the emotional issues untreated (Hart et al., 2022). Family caregivers know that patients with COPD can suffer from anxiety during exacerbations and that anxiety can worsen the dyspnoea, activating a vicious circle (Robinson et al., 2018). They try to reassure and calm patients down and give them a sense of control and safety (Ferreira et al., 2020). The support provided by family caregivers in self-care management has been shown to decrease emergency service utilization and patient hospitalization (Wakabayashi et al., 2011).

4.4 | Implication for practice and research

Nurses should acknowledge the importance of family caregivers' contributions to patient self-care and be aware of what family caregivers do daily to support patients in self-care. Research has pointed out that patients with chronic diseases and their family caregivers should be considered as a dyad of care (De Maria et al., 2021). Therefore, nurses should assess family caregiver contributions to patient's self-care in their clinical practice, using valid and reliable instruments, such as the Caregiver Contribution to Self-Care of COPD Inventory (CC-SC-COPDI) (Matarese et al., 2022) and evaluate which contributions are the most effective and which ones can be modified to improve patient self-care and reduce the

family caregiver burden. Family caregivers should be included in self-management education programmes and be considered as the target of interventions together with the patients affected by COPD. Moreover, nurses should provide information and disease-related education in every encounter with family caregivers and patients with COPD to reinforce their knowledge and skills, such as during hospitalization, at each clinic visit and home care access. Nurses should also provide information to caregivers on and facilitate access to the social and financial benefits that could help them to fulfil their role.

We acknowledge that contributions to self-care could be influenced by family caregiver and patient gender and family relationship (Nakken et al., 2016), even though we could not find any relevant differences in the narratives of our sample. Future quantitative research should assess the influence of gender and type of family relationship (spouse/partner or children) on the contributions to COPD patient self-care and on patient self-care.

4.5 | Limitations

This study has some limitations. First, the participants were recruited in a specific region of Italy, therefore the reported experiences of family caregivers might be influenced by the health services for patients with COPD available in that region and this could influence the transferability of the results. Second, due to restrictions on visits to hospital during the COVID-19 pandemic, family caregiver recruitment was almost entirely done in clinics, although we had planned to recruit in different healthcare settings, such as hospital units. Therefore, we cannot exclude the possibility that this population could present additional experiences of caregiver contributions. Lastly, due to the need to reduce personal contact during the pandemic, most of the interviews were conducted by telephone; it is possible that the lack of personal interaction may have influenced the complete sharing of caregiver experiences, even though the interviewers met the participants personally during the recruitment phase, establishing personal contact.

5 | CONCLUSIONS

Family caregivers perform a variety of behaviours when taking on responsibility for supporting patients with COPD in self-care, especially when patients are more dependent and the disease more severe. Caregivers provide practical and emotional support, and their contribution is essential to improve treatment adherence, to enable the patient to continue living a normal life, and to have access to the health services. Family caregivers are constantly vigilant and monitor patients daily to detect worsening conditions, and they deal with exacerbations especially when patients are unable to do so due to their critical condition. Nurses should acknowledge the various contributions provided by family caregivers and consider them as collaborators in the care of patients with COPD.

AUTHOR CONTRIBUTIONS

Roberta Pandoni, Maria Matarese, Giulia Pecorari: Made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data. **Roberta Pandoni, Beatrice Albanesi, Marco Clari and Maria Matarese:** Involved in drafting the manuscript or revising it critically for important intellectual content. **Roberta Pandoni, Beatrice Albanesi, Marco Clari and Maria Matarese:** Given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content. **Roberta Pandoni, Maria Matarese and Beatrice Albanesi:** Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

ACKNOWLEDGEMENTS

The authors thank all the family caregivers who participated in the study.

FUNDING INFORMATION

This research was funded by the Centre of Excellence for Nursing Scholarship (CECRI), Rome, Italy, grant number 2.21.15.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

PEER REVIEW

The peer review history for this article is available at <https://www.webofscience.com/api/gateway/wos/peer-review/10.1111/jan.15939>.

DATA AVAILABILITY STATEMENT

Data available on request from the authors.

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REFERENCES

- Andersen, I. C., Thomsen, T. G., Bruun, P., Bødtger, U., & Hounsgaard, L. (2017). Patients' and their family members' experiences of participation in care following an acute exacerbation in chronic obstructive pulmonary disease: A phenomenological-hermeneutic study. *Journal of Clinical Nursing*, 26(23–24), 4877–4889.
- Atlas.ti. (2022). *Scientific software development GmbH*. <https://atlasti.com>
- Bendixen, H. J., Ejlersen Wæhrens, E., Wilcke, J. T., & Sørensen, L. V. (2014). Self-reported quality of ADL task performance among patients with COPD exacerbations. *Scandinavian Journal of Occupational Therapy*, 21(4), 313–320.
- Bove, D. G., Zakrisson, A. B., Midtgaard, J., Lomborg, K., & Overgaard, D. (2016). Undefined and unpredictable responsibility: A focus group study of the experiences of informal caregiver spouses of patients with severe COPD. *Journal of Clinical Nursing*, 25(3–4), 483–493. <https://doi.org/10.1111/jocn.13076>
- Bryant, J., Mansfield, E., Boyes, A., Waller, A., Sanson-Fisher, R., & Regan, T. (2016). Involvement of informal caregivers in supporting patients with COPD: A review of intervention studies. *International Journal of Chronic Obstructive Pulmonary Disease*, 11, 1587–1596. <https://doi.org/10.2147/copd.s107571>
- Chen, Z., Fan, V. S., Belza, B., Pike, K., & Nguyen, H. Q. (2017). Association between social support and self-care behaviors in adults with chronic obstructive pulmonary disease. *Annals of the American Thoracic Society*, 14(9), 1419–1427.
- Crawford, G., Brooksbank, M., Brown, M., Burgess, T., & Young, M. (2013). Unmet needs of people with end-stage chronic obstructive pulmonary disease: Recommendations for change in Australia. *Internal Medicine Journal*, 43(2), 183–190.
- Cruz, J., Marques, A., & Figueiredo, D. (2017). Impacts of COPD on family carers and supportive interventions: A narrative review. *Health & Social Care in the Community*, 25(1), 11–25.
- De Maria, M., Ausili, D., Lorini, S., Vellone, E., Riegel, B., & Matarese, M. (2022). Patient self-care and caregiver contribution to patient self-care of chronic conditions: What is dyadic and what is not. *Value in Health*, 25(7), 1165–1173. <https://doi.org/10.1016/j.jval.2022.01.007>
- De Maria, M., Ferro, F., Ausili, D., Buck, H. G., Vellone, E., & Matarese, M. (2021). Characteristics of dyadic care types among patients living with multiple chronic conditions and their informal caregivers. *Journal of Advanced Nursing*, 77(12), 4768–4781.
- Doos, L., Bradley, E., Rushton, C. A., Satchithananda, D., Davies, S. J., & Kadam, U. T. (2015). Heart failure and chronic obstructive pulmonary disease multimorbidity at hospital discharge transition: A study of patient and carer experience. *Health Expectations*, 18(6), 2401–2412.
- Duarte-de-Araújo, A., Teixeira, P., Hespanhol, V., & Correia-de-Sousa, J. (2018). COPD: Understanding patients' adherence to inhaled medications. *International Journal of Chronic Obstructive Pulmonary Disease*, 13, 2767–2773.
- Durante, A., Paturzo, M., Mottola, A., Alvaro, R., Dickson, V. V., & Vellone, E. (2019). Caregiver contribution to self-care in patients with heart failure: A qualitative descriptive study. *Journal of Cardiovascular Nursing*, 34(2), E28–E35.
- Family Caregiver Alliance. (2023). *Caregivers count too! Section 1: Definitions*. Retrieved August 19, 2023, from <https://www.caregiver.org/resource/caregivers-count-too-s1-definitions/>
- Ferreira, D. H., Kochovska, S., Honson, A., Phillips, J. L., & Currow, D. C. (2020). Two faces of the same coin: A qualitative study of patients' and carers' coexistence with chronic breathlessness associated with chronic obstructive pulmonary disease (COPD). *BMC Palliative Care*, 19(1), 1–12.
- Gatti, V., Banfi, P., Centanni, S., D'Antonio, S., Giustini, S., Piraino, A., Zibellini, M., & Marini, M. G. (2018). Enlightening chronic obstructive pulmonary disease through patients' and caregivers' narratives. *International Journal of Chronic Obstructive Pulmonary Disease*, 13, 3095–3105.
- Gautun, H., Werner, A., & LurÅs, H. (2012). Care challenges for informal caregivers of chronically ill lung patients: Results from a questionnaire survey. *Scandinavian Journal of Public Health*, 40(1), 18–24.
- Giacomini, M., DeJean, D., Simeonov, D., & Smith, A. (2012). Experiences of living and dying with COPD: A systematic review and synthesis of the qualitative empirical literature. *Ontario Health Technology Assessment Series*, 12(13), 1.
- Giordano, V., Iovino, P., Corvese, F., Vellone, E., Alvaro, R., & Villa, G. (2022). Caregiver contribution to self-care and its associated variables among caregivers of ostomy patients: Results of a cross-sectional study. *Journal of Clinical Nursing*, 31(1–2), 99–110.
- GOLD. (2023). *Global strategy for the diagnosis, management, and prevention of chronic obstructive pulmonary disease*. Global initiative for chronic obstructive lung disease. Retrieved from www.goldcopd.org
- Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24(2), 105–112.

- Grant, M., Cavanagh, A., & Yorke, J. (2012). The impact of caring for those with chronic obstructive pulmonary disease (COPD) on carers' psychological well-being: A narrative review. *International Journal of Nursing Studies*, 49(11), 1459–1471.
- Hart, J. L., Hong, D., Summer, A., & Schnoll, R. A. (2022). Stakeholders' views on reducing psychological distress in chronic obstructive pulmonary disease. *Journal of Pain and Symptom Management*, 63(1), e21–e28. <https://doi.org/10.1016/j.jpainsymman.2021.06.021>
- Hynes, G., Stokes, A., & McCarron, M. (2012). Informal care-giving in advanced chronic obstructive pulmonary disease: Lay knowledge and experience. *Journal of Clinical Nursing*, 21(7–8), 1068–1077. <https://doi.org/10.1111/j.1365-2702.2011.03944.x>
- Iovino, P., Lyons, K. S., De Maria, M., Vellone, E., Ausili, D., Lee, C. S., Riegel, B., & Matarese, M. (2021). Patient and caregiver contributions to self-care in multiple chronic conditions: A multilevel modelling analysis. *International Journal of Nursing Studies*, 116, 103574.
- Kerr, C., Nixon, A., & Wild, D. (2010). Assessing and demonstrating data saturation in qualitative inquiry supporting patient-reported outcomes research. *Expert Review of Pharmacoeconomics & Outcomes Research*, 10(3), 269–281.
- Kim, Y. J., Lee, B. K., Jung, C. Y., Jeon, Y. J., Hyun, D. S., Kim, K. C., Yu, S. K., Choi, H. S., Shin, W. H., & Lee, K. H. (2012). Patient's perception of symptoms related to morning activity in chronic obstructive pulmonary disease: The SYMBOL study. *The Korean Journal of Internal Medicine*, 27(4), 426–435.
- Lippiett, K. A., Richardson, A., Myall, M., Cummings, A., & May, C. R. (2019). Patients and informal caregivers' experiences of burden of treatment in lung cancer and chronic obstructive pulmonary disease (COPD): A systematic review and synthesis of qualitative research. *BMJ Open*, 9(2), e020515.
- Macdonald, M., Lang, A., Storch, J., Stevenson, L., Donaldson, S., Barber, T., & Iaboni, K. (2013). Home care safety markers: A scoping review. *Home Health Care Services Quarterly*, 32(2), 126–148.
- Marques, A., Cruz, J., & Brooks, D. (2021). Interventions to support informal caregivers of people with chronic obstructive pulmonary disease: A systematic literature review. *Respiration*, 100(12), 1230–1242.
- Matarese, M., Lyons, K. S., Piredda, M., & De Marinis, M. G. (2023). Disease-related knowledge in people with chronic obstructive pulmonary disease and their informal caregivers: A multilevel modelling analysis. *Journal of Clinical Nursing*, 32(13–14), 3543–3556. <https://doi.org/10.1111/jocn.16433>
- Matarese, M., Pandoni, R., Ausili, D., Vellone, E., & De Maria, M. (2022). Validity and reliability of caregiver contribution to self-care of chronic obstructive pulmonary disease inventory and caregiver self-efficacy in Contributing to Self-Care Scale. *Evaluation & the Health Professions*, 46(3), 255–269.
- Matarese, M., Pandoni, R., Piredda, M., & De Marinis, M. G. (2021). Caregivers' experiences of contributing to patients' self-care in chronic obstructive pulmonary disease: A thematic synthesis of qualitative studies. *Journal of Advanced Nursing*, 77(10), 4017–4034.
- Morse, J., & Field, P. (1996). *Nursing research: The application of qualitative approaches* (2nd ed.). Chapman and Hall.
- Nakken, N., Janssen, D. J., van Vliet, M., de Vries, G. J., Clappers-Gielen, G. A., Michels, A. J., Muris, J. W., Vercoulen, J. H., Wouters, E. F., & Spruit, M. A. (2016). Gender differences in partners of patients with COPD and their perceptions about the patients. *International Journal of Chronic Obstructive Pulmonary Disease*, 12, 95–104.
- Nakken, N., Janssen, D. J. A., van den Bogaart, E. H. A., Wouters, E. F. M., Franssen, F. M. E., Vercoulen, J. H., & Spruit, M. A. (2015). Informal caregivers of patients with COPD: Home sweet home? *European Respiratory Review*, 24(137), 498–504.
- Prarach, R., & Ua-Kit, N. (2023). Predicting factors of dietary behaviors among patients with chronic obstructive pulmonary disease. *Chulalongkorn Medical Journal*, 67(3), 175–181. <https://doi.org/10.14456/clmj.2023.23>
- Raptis, D. G., Rapti, G. G., Papathanasiou, I. V., Papagiannis, D., Gourgoulanis, K. I., & Malli, F. (2021). Level of knowledge about COPD among patients and caregivers. *Advances in Experimental Medicine and Biology*, 1337, 299–305. https://doi.org/10.1007/978-3-030-78771-4_33
- Riegel, B., Jaarsma, T., & Strömberg, A. (2012). A middle-range theory of self-care of chronic illness. *Advances in Nursing Science*, 35(3), 194–204.
- Robinson, K., Lucas, E., van den Dolder, P., & Halcomb, E. (2018). Living with chronic obstructive pulmonary disease: The stories of frequent attenders to the emergency department. *Journal of Clinical Nursing*, 27(1–2), 48–56. <https://doi.org/10.1111/jocn.13842>
- Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health*, 23(4), 334–340.
- Strang, S., Osmanovic, M., Hallberg, C., & Strang, P. (2018). Family caregivers' heavy and overloaded burden in advanced chronic obstructive pulmonary disease. *Journal of Palliative Medicine*, 21(12), 1768–1772. <https://doi.org/10.1089/jpm.2018.0010>
- Suresh, M., Young, J., Fan, V., Simons, C., Battaglia, C., Simpson, T. L., Fortney, J. C., Locke, E. R., & Trivedi, R. (2022). Caregiver experiences and roles in care seeking during COPD exacerbations: A qualitative study. *Annals of Behavioral Medicine*, 56(3), 257–269.
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349–357.
- Trivedi, R. B., Bryson, C. L., Udris, E., & Au, D. H. (2012). The influence of informal caregivers on adherence in COPD patients. *Annals of Behavioral Medicine*, 44(1), 66–72. <https://doi.org/10.1007/s12160-012-9355-8>
- Vagharseyyedin, S. A., Arbabi, M., Rahimi, H., & Moghaddam, S. G. M. (2022). Effects of a caregiver educational program on interactions between family caregivers and patients with advanced COPD. *Home Healthcare Now*, 40(2), 75–81.
- Vellone, E., Riegel, B., & Alvaro, R. (2019). A situation-specific theory of caregiver contributions to heart failure self-care. *The Journal of Cardiovascular Nursing*, 34(2), 166–173. <https://doi.org/10.1097/jcn.0000000000000549>
- Vestbo, J., Hurd, S. S., Agustí, A. G., Jones, P. W., Vogelmeier, C., Anzueto, A., Barnes, P. J., Fabbri, L. M., Martinez, F. J., & Nishimura, M. (2013). Global strategy for the diagnosis, management, and prevention of chronic obstructive pulmonary disease: GOLD executive summary. *American Journal of Respiratory and Critical Care Medicine*, 187(4), 347–365.
- Wakabayashi, R., Motegi, T., Yamada, K., Ishii, T., Gemma, A., & Kida, K. (2011). Presence of in-home caregiver and health outcomes of older adults with chronic obstructive pulmonary disease. *Journal of the American Geriatrics Society*, 59(1), 44–49.
- Wilson, A. M. M. M., Almeida, G. S. M., Santos, B. D. C. F., Nakahara-Melo, M., Conceição, A. P., & Cruz, D. A. L. M. (2022). Factors associated with caregivers' contribution to self-care in heart failure. *Revista Latino-Americana de Enfermagem*, 30, e3632.

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Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Pandoni, R., Albanesi, B., Clari, M., Pecorari, G., & Matarese, M. (2024). Contributing to self-care of a person with chronic obstructive pulmonary disease: A qualitative study of the experiences of family caregivers. *Journal of Advanced Nursing*, 80, 1927–1942. <https://doi.org/10.1111/jan.15939>

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