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Original Article

The experience and perspectives of caregivers caring for their family members with chronic obstructive pulmonary disease during the six months following hospital discharge: study protocol and preliminary results

L'esperienza e le prospettive dei caregiver che assistono i loro familiari affetti da broncopneumopatia cronica ostruttiva nei sei mesi successivi alla dimissione ospedaliera: protocollo di studio e risultati preliminari

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Key words: Chronic Obstructive Pulmonary Disease (COPD), caregiver experiences, informal caregivers, hospital discharge.

ABSTRACT

Background: Chronic Obstructive Pulmonary Disease (COPD) is a global health issue. This study explores the experiences and perspectives of informal caregivers caring for family members with COPD in the six months following hospital discharge.
Materials and Methods: a prospective qualitative study was conducted using semi-structured interviews with carers of patients with COPD. The interviews, analysed using Colaizzi's phenomenological method, explored the participants' lived experiences. A minimum of 20 carers were enrolled, with data saturation as the criterion for sample size.
Results: preliminary results highlighted three main themes, the emotional and psychological impact on caregivers, changes in daily routines, and difficulties in balancing personal and professional life. A strong need for support from caregivers and improved relationships with health professionals also emerged.
Conclusions: the study highlights the importance of more resources and training for caregivers to improve the quality of life for both patients and caregivers. Good interaction between carers and patients can reduce rehospitalisation and improve care at home.

Background: la Broncopneumopatia Cronica Ostruttiva (BPCO) è un problema di salute globale. Questo studio esplora l'esperienza dei caregiver informali che assistono i familiari con BPCO nei sei mesi successivi alla dimissione ospedaliera.
Materiali e Metodi: è stato condotto uno studio qualitativo prospettico basato su interviste semi-strutturate con caregiver di pazienti affetti da BPCO. Le interviste, analizzate con il metodo fenomenologico di Colaizzi, hanno esplorato le esperienze vissute dai partecipanti. Sono stati reclutati almeno 20 caregiver, con la saturazione dei dati come criterio per la dimensione del campione.
Risultati: i risultati preliminari hanno evidenziato tre temi principali, l'impatto emotivo e psicologico sui caregiver, le modifiche delle abitudini quotidiane e le difficoltà nel bilanciare vita privata e lavorativa. È emerso anche un forte bisogno di supporto da parte degli operatori sanitari e un miglioramento delle relazioni con i professionisti della salute.
Conclusioni: lo studio sottolinea l'importanza di maggiori risorse e formazione per i caregiver, migliorando la qualità della vita di pazienti e caregiver. Una buona interazione tra caregiver e operatori sanitari può ridurre le riospedalizzazioni e migliorare l'assistenza domiciliare.

Introduction

Chronic Obstructive Pulmonary Disease (COPD) affects millions of adults worldwide and is becoming a significant burden on healthcare systems in many countries.[1] Data shows that most individuals living with a COPD diagnosis are over the age of 40. Today, COPD is one of the leading causes of morbidity and mortality globally.[2] Many COPD patients are cared for at home, often with the support of an informal caregiver, who is usually a family member. These individuals are typically unpaid and untrained, providing care as part of their personal relationship with the patient.

In the past two decades, family caregiving (informal care) has become increasingly common in Western countries as people live longer with chronic illnesses and the population ages. The development of systems that shift care away from hospitals and into the community has shown considerable benefits, contributing to a significant trend that is likely to continue. However, this means that more and more relatives and family members will become informal caregivers, which will have a substantial impact on their lives. Additionally, the caregiving role often falls on the adult children of elderly individuals, particularly daughters.[3] COPD is a pathological process in which patients' conditions fluctuate between periods of acute exacerbation, requiring hospitalization, and periods of recovery with less severe symptoms. After hospital discharge following an acute episode, many COPD patients are cared for by family members.[4]

Therefore, understanding the impact of the disease on both the patient and the caregiver is crucial for healthcare providers to support informal caregivers and ensure that the home remains a therapeutic environment where the caregivers' concerns are acknowledged and addressed.[5] The growing number of informal caregivers has drawn the attention of researchers, as their role is increasingly recognized by healthcare professionals. The critical role they play when a patient with a complex medical condition returns home after hospitalization is vital in terms of preventing readmissions and ensuring a safe home care environment.[6] In fact, informal caregivers often act as a bridge between healthcare providers, who manage acute hospital care and plan discharge and home-based self-management.[7] However, although their role is essential, there is growing evidence that informal caregivers may experience significant stress and disruption in their lives due to the caregiving role, with some describing the experience as being "between hope and despair." Informal caregivers may also feel that their efforts go unrecognized by healthcare professionals, which can have a detrimental effect on their emotional well-being.[8] Furthermore, healthcare providers have a role to play when there are discrepancies between the care needs expressed by the patient and the care needs identified by the informal caregiver. There is increasing recognition that caring for someone with a chronic condition can disrupt the caregiver's life and be harmful to their physical, social, and emotional health, and that meeting caregivers' needs is important because it ultimately affects the care experienced by the patient upon returning home.[9] Some researchers have found that home care can be particularly disruptive for those with advanced COPD and that support from healthcare professionals is important for caregivers who must adapt to the new and additional demands placed upon them.

Addressing these concerns can make the difference between a patient being able to remain at home or being readmitted to the hospital. Understanding the dynamics between the caregiver and the patient once they return home is crucial for healthcare providers to effectively manage the entire family. Many caregivers feel responsible for their relatives and want to be actively involved in providing care, but they also want to feel supported and competent, as guided by healthcare professionals.[10]

The life-altering impact of being an informal caregiver for a relative with COPD is evident from the review of studies exploring the relationship between informal caregivers and COPD.[11] However, studies on COPD caregiving have predominantly been conducted in the United States or Northern Europe. There are no studies exploring this phenomenon in a Southern European context, representing a significant gap given the differences in cultural beliefs about family, the role of family members in elder care, and the different approaches to hospital discharge and primary care that exist between Northern and Southern Europe.

The aim of this study is to explore the experiences and support needs of informal caregivers of patients with COPD during the six months following discharge. The six-month period is significant as it includes the first two months with planned hospital follow-up and the subsequent months during which the caregiver must navigate a path where they may feel alone.

Objectives

The aim of the study is to explore caregivers 'experiences to gain a deeper understanding of their challenges, emotions and adaptive strategies in caring for a family member with COPD. Furthermore, the study aims to improve the clinical, relational and organizational management of COPD patients during the first six months after hospital discharge.

Materials and Methods

This is a prospective, non-profit qualitative observational study aimed at improving clinical practice as an integral part of healthcare, not for industrial purposes, in accordance with D.M. 30-11-2021 (non-profit experimentation). Free and narrative interviews will be conducted, with a phenomenological analysis of the data according to Colaizzi (1978),[12] which provides a phenomenological approach designed to elicit lived experiences from participants as well as to explore their motivations and actions.[13] This study has been designed and reported following the consolidated criteria for reporting qualitative research (COREQ) checklist.[14]

The study population consists of caregivers of patients who have been hospitalized in the Respiratory Diseases Department of Italian hospitals. They will be enrolled using a convenience sampling method.

While it is not possible to define the exact number of participants a priori, a minimum of 20 subjects will be enrolled, selected according to the inclusion criteria. Recruitment in qualitative research should, in fact, conclude based on the achievement of saturation. Since it is not possible to predict when saturation will be reached, the sample size is established a priori based on Creswell's methodological indications[15] and considering that the interviews may be very brief and thus less informative.

The study is expected to last a total of 12 months from the date of obtaining the favorable opinion of the Territorial Ethics Committee and the authorization from the General Director of the University Hospital of Alessandria.

Study procedures

The Principal Investigator (PI) of the study will contact a minimum of 50 participants among the caregivers of patients who have been hospitalized in the Respiratory Diseases Departments of selected hospitals in Italy, proposing their participation in the study. In the case of a positive response, the PI will request permission to share the participant's name with the research team, who will then contact the participant via email. At that time, they will also send the information sheet, the informed consent form, and the data processing form. A few days after sending the email, the

researchers will follow up with the participant, and if they confirm their willingness to participate, they will agree on a suitable time and place for the interview. This interview can be conducted either in person or through an electronic platform, based on the caregiver's preference.

Data collection strategies

Data will be collected through individual, free, and narrative interviews conducted at a time chosen by the participant. This type of interview includes a single initial question: "Tell me about the experiences and challenges you encountered while caring for your family member in the six months following hospital discharge."

The interviewer may use additional prompting questions to encourage the participant to elaborate and enrich their narrative. Through probing questions, the researcher encourages the interviewee to clarify their responses, ease their defenses, and verify the interpretation of their answers. The interviewer is required to formulate questions appropriately in real-time, calibrating them to the interlocutor, using suitable language, and, when appropriate, employing the exact words of the interviewees.

The interview may be conducted either in person or through an electronic platform, based on the interviewee's needs. It is expected to last between 10 and 60 minutes and will be audio-recorded with the participant's consent. The duration will be determined by the participant and their narrative. Each interview will be transcribed verbatim. Following the transcription and anonymization, every audio recording of the interview will be deleted, with the participant's consent. The interviews will be transcribed while omitting any data and information that could reveal the participants' identities. Some socio-demographic information will also be collected to describe the types and main characteristics of the participants.

Data analysis

The interviews will be digitally recorded and transcribed verbatim. The data will be analyzed according to the phenomenological analysis method described by Colaizzi (1978).[12] This process will include verbatim transcription of recordings and complete reading; division into conversation sequences and definition of initial labels; combining the labels to identify main themes and subthemes; description of conversational acts and main themes; and writing the initial report of results. The data analysis will be conducted by the entire research team.

Preliminary results

Some significant results have emerged from the initial interviews, which include key themes such as the emotional and psychological impact on the quality of life of both caregivers and patients affected by COPD, changes in daily habits with difficulties in maintaining work, and the relationship with healthcare professionals.

Discussion

This study aims to explore the lived experiences of caregivers caring for family members with COPD during the six months following hospital discharge. Informal caregivers are pivotal in the home management of COPD, yet they face a multitude of challenges as they address not only the patient's physical needs but also their emotional and psychological well-being. This dual responsibility often leads to increased stress levels, social isolation, and changes in family dynamics.[16]

The preliminary results highlight key challenges faced by caregivers, including emotional and psychological distress, difficulties in balancing daily routines, and interactions with healthcare professionals**.** This aligns with previous research demonstrating that caregivers of patients with chronic illnesses often experience increased psychological distress, heightened risk of anxiety and depression[17] that significantly affects their level of quality of life. The reason is that COPD patients have a long disease duration, recurrent symptoms, and progressive exacerbations, which cause an unusually high burden of care for their caregivers and leave them vulnerable to many physical impairments during the long-term, continuous care process.[18,19]

Peters *et al*.[20] also highlight how a systems approach can help healthcare professionals identify all the individual and structural factors involved in the transition from hospital to home for people with chronic illness to improve planning and support for caregivers at home.

Such issues underscore the need for a more integrated and continuous support system that not only focuses on the clinical aspects of patient care but also actively addresses the psychosocial needs of the caregivers.

Conclusions

Caregivers reported difficulties balancing their personal and work lives with caregiving responsibilities, highlighting the need for better training and additional resources to facilitate their role. Furthermore, it emerged that their experience can directly influence the progression of the patient's illness, emphasizing the importance of psychological and practical support that can enhance not only the well-being of the patient but also that of the caregiver.

Considering these results, it is essential for healthcare professionals to recognize the crucial role of caregivers in managing COPD by implementing integrated care pathways that include support interventions dedicated to family members as well. This approach will help prevent caregiver burnout, improve the quality of care provided to patients, and reduce the risk of readmissions.

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Informed consent: the study included carers of COPD patients over the age of 18 who had had at least one hospital visit and provided ongoing care without financial compensation; they also signed an informed consent form.

Availability of data and materials: data will be available upon request from the authors.

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