

Original Article

Self-perception of the patient with chronic obstructive pulmonary disease on their occupational performance during the COVID-19 pandemic¹

Autopercepção do paciente com doença pulmonar obstrutiva crônica sobre seu desempenho ocupacional em tempo de pandemia de COVID-19

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Abstract

Introduction: Chronic Obstructive Pulmonary Disease (COPD) is characterized by progressive airflow limitation. Patients also develop systemic manifestations that determine the progressive decline in functional capacity. **Objective:** To understand the self-perception of patients with COPD about their occupational performance, highlighting the influence of the COVID-19 pandemic in their daily lives. **Method:** Descriptive research with a qualitative approach, with the technique of content analysis in the thematic modality. The sample consisted of nine patients with COPD treated in the post-rehabilitation pulmonary maintenance program at a healthcare referral hospital in cardiopneumology. Data collection took place from June to August 2020, through a semi-structured interview script on telephone calls. The recorded interviews were transcribed and subjected to content analysis through thematic analysis. **Results:** The daily occupations perceived as being difficult to perform as a result of COPD were sleep, work, social participation, leisure, in addition to Activities of Daily Living (ADL) - functional mobility, bathing, personal hygiene, getting dressed and sexual activity - and Activities Instrumentals of Daily Living (IADL) – home establishment and management and

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shopping. Occupations limited by COPD were even more impacted by the restrictive measures due to COVID-19. **Conclusion:** Based on the understanding of the difficulties of patients with COPD in carrying out their occupations, it was possible to know how much COPD affects occupational performance and interferes in the most diverse occupations that bring meaning and purpose to life. The COVID-19 pandemic further limited COPD patient involvement in their significant occupations.

Keywords: Pulmonary Disease, Chronic Obstructive, Activities of Daily Living, COVID-19, Occupational Therapy.

Resumo

Introdução: A Doença Pulmonar Obstrutiva Crônica (DPOC) é caracterizada pela limitação progressiva do fluxo aéreo. Os pacientes também desenvolvem manifestações sistêmicas que determinam o declínio progressivo da capacidade funcional. **Objetivo:** Conhecer a autopercepção do paciente com DPOC sobre seu desempenho ocupacional destacando a influência da pandemia de COVID-19 no seu cotidiano. **Método:** Pesquisa de natureza descritiva e abordagem qualitativa, tendo como técnica a análise de conteúdo na modalidade temática. A amostra foi constituída de nove pacientes com DPOC atendidos no programa de manutenção pós-reabilitação pulmonar em hospital de referência de saúde em cardiopneumologia. A coleta dos dados ocorreu de junho a agosto de 2020, mediante roteiro de entrevista semiestruturada, por meio de chamadas telefônicas. As entrevistas gravadas foram transcritas e submetidas à análise do conteúdo, por meio da análise temática. **Resultados:** As ocupações cotidianas percebidas com dificuldade de serem realizadas em decorrência da DPOC foram sono, trabalho, participação social, lazer, além de Atividades de Vida Diária (AVD) – mobilidade funcional, banho, higiene pessoal, vestir e atividade sexual – e Atividades Instrumentais da Vida Diária (AIVD) – gerenciamento do lar e fazer compras. As ocupações limitadas pela DPOC foram ainda mais impactadas pelas medidas restritivas causadas pela COVID-19. **Conclusão:** Com base na compreensão das dificuldades do paciente com DPOC em realizar suas ocupações, foi possível conhecer o quanto a DPOC repercute no desempenho ocupacional e interfere nas mais diversas ocupações que trazem significado e propósito à vida. A pandemia de COVID-19 limitou ainda mais o envolvimento do paciente com DPOC nas suas ocupações significativas.

Palavras-chave: Doença Pulmonar Obstrutiva Crônica, Atividades Cotidianas, COVID-19, Terapia Ocupacional.

Introduction

Chronic Obstructive Pulmonary Disease (COPD) is a preventable and treatable disease characterized by airflow limitation that is not fully reversible. This airflow limitation is usually progressive and associated with an abnormal lung inflammatory response to harmful particles and/or gases, with smoking being the main risk factor (Global Initiative for Chronic Obstructive Lung Disease, 2021).

Currently, COPD is one of the leading causes of chronic morbidity and the third leading cause of death in the world, responsible for 3.2 million deaths in 2017, with an estimated progressive increase in this number in the coming years (Roth et al., 2018). In Brazil, it is the

third leading cause of death among chronic non-communicable diseases (Rabahi, 2013). COPD will remain a significant public health problem in the future due to continued exposure to risk factors and an aging population (Rabe & Watz, 2017; Global Initiative for Chronic Obstructive Lung Disease, 2021).

Pulmonary dysfunction, systemic manifestations and increased dyspnea can lead to progressive worsening of physical fitness, exercise intolerance and inactivity in patients with COPD, determining a progressive decline in functional capacity, impacting occupational performance (Kim et al., 2008; Silva et al., 2017).

Dyspnea, characterized by difficulty breathing, is the most limiting symptom. Patients with greater complaints of tiredness have a worse condition to carry out daily activities. The greater the feeling of shortness of breath, the more predominant will be their limitation and restriction in performing daily activities (Silva et al., 2015).

According to Machado (2018), the progression of lung diseases leads to worsening of symptoms, causing progressive limitation of daily activities. This limitation can become a vicious cycle and evolve into the individual's functional dependence, altering their social, economic and emotional life, factors that can interfere with their quality of life.

Thus, it is necessary that the therapeutic approaches offered to patients with COPD not only objectively measure performance, physiological responses and dyspnea when performing daily activities, but also the impact that these difficulties and limitations have on their occupations (Gulart et al., 2015).

Occupations refer to the everyday activities that people carry out as individuals, in families and in communities, to occupy their time and bring meaning and purpose to life; they include the activities that people need, want, and should do (World Federation of Occupational Therapy, 2020).

Occupational therapy has as its principle the key elements of occupational performance with purposes that enable and allow patients to perform their significant tasks, thus enabling personal satisfaction and well-being, minimizing the difficulties and limitations to perform their occupations as a result of their disease. The patient is encouraged to be actively involved throughout the process, in order to achieve goals that are meaningful and relevant to their daily life (Hagedorn, 2003).

The performance of their occupations should be determined by the patients themselves based on their experiences. No one better than himself or herself to determine how they perform their daily occupations (Caldas et al., 2011). It is up to the occupational therapist to know the client's perception of their occupational performance and use it as a guide based on a client-centered practice. According to the American Occupational Therapy Association (2020), when using a client-centered approach, the occupational therapy professional gathers information to understand what, at that moment, is important and meaningful to the patient.

The interest in this research emerged during the researcher's experience as an occupational therapist residing in a reference hospital in the care of patients with COPD, when she realized the need to reflect on the occupational performance that is part of the routine of these patients, as well as the influence of the COVID-19 pandemic in these occupations.

This research is justified by the perceived need during care for patients with COPD to provide space and focus on their relational and significant aspects, seeking to understand the self-perception of these patients in relation to their occupational performance. As it was carried out during the COVID-19 pandemic, it was also possible to highlight the influence of the interruption and deprivation of occupations at that time. From this, the objective of this

research was to know the self-perception of patients with COPD about their occupational performance, also highlighting the influence of COVID-19 in their daily lives.

Method

Type of research

This is a descriptive study with a qualitative approach. According to Minayo (2014), qualitative study deals with the universe of meanings, beliefs, values and attitudes, which fits into a deeper space of relationships, processes and phenomena that cannot be reduced to operationalization of variables, favoring the interpretation of particularities of individual behaviors and attitudes, having as a technique the content analysis in the thematic modality (Bardin, 2009).

Research location

The study was conducted at Hospital Dr. Carlos Alberto Studart Gomes (Hospital de Messejana), specialized in the diagnosis and treatment of cardiac and pulmonary diseases, in the city of Fortaleza-CE, a reference center in the provision of health services in cardiology and pulmonology in the North and Northeast region of the country.

Participants of the research

The study population consisted of patients with COPD who participate in the post-pulmonary rehabilitation maintenance program called “Caminhada do Bosque” – in free translation, “Walk of the Woods” - a program designed with the objective of maintaining the benefits achieved after discharge from pulmonary rehabilitation, avoiding reduction functional loss caused by lung disease and favoring the optimization of physical, emotional and social activities, providing the patient with the maximization and maintenance of their independence and autonomy.

The sample consisted of 9 (nine) people of both sexes, aged between 57 and 78 years. Respondents were identified using numbers according to the order of the interview, so that the real identity of each participant was preserved. P1 was used for patient number 1, successively following the numbering required until P9, the total number of patients interviewed. They were selected according to the following inclusion criteria: clinical diagnosis of COPD, regardless of disease stage; discharge received from the pulmonary rehabilitation program; and frequent participation in the post-rehabilitation pulmonary maintenance program, the “Caminhada do Bosque”. For the exclusion criteria, severe hearing impairment was considered, which would certainly impede understanding of the objectives and participation in the present study, as well as having the telephone temporarily turned off or outside the coverage area during contact attempts.

Data collection

The collection of information took place from June to August 2020. Data corresponding to occupations were obtained qualitatively through the use of a semi-structured interview

script, through telephone calls due to the suspension of face-to-face assistance due to the pandemic of COVID-19.

The recorded interviews were transcribed and subjected to content analysis, using Bardin's thematic modality, which aims to overcome uncertainty, confirming or not what is believed to be seen in the message. Reading the material leads to validation and generalization of the data, enriching the reading by discovering content and structures that confirm or deny what is sought to demonstrate, regarding messages and meaning elements (Bardin, 2009).

Full transcripts were carried out with the preservation of maximum fidelity between the dialogue and the written text, which allowed the researcher to perceive the dimension of the impact that COPD causes in the lives of the subjects and what it was like to fail to carry out their significant occupations during the period of pandemic, in addition to the intrinsic feelings and other meanings that arose.

Ethical considerations

In terms of ethical aspects that supported the study, the requirements of resolution 466/12 of the National Health Council, which provides standards and regulatory guidelines for research involving human beings, were complied with. This study was approved by the Research Ethics Committee of the Hospital Dr. Carlos Alberto Studart Gomes, under opinion number 3.927.816 and Certificate of Presentation of Ethical Appreciation (CAAE) number 29585520.6.0000.5039. All patients present in the sample expressed their consent to participate in the research through the free and informed consent by telephone in the first contact.

Data analysis

To more precisely reach the manifest and latent meanings brought by the patients to the data, they were submitted to Bardin's (2009) content analysis, highlighting the units of meaning, thematic categories and essential ideas.

The trajectory of analysis of the speeches of patients with COPD about their self-perception of occupational performance took place initially with the transcription of the recorded interviews. After reading, independent reductions were performed, reached by convergence zones between the patients' statements, from which the units of meaning were removed, starting the conduction of the coding, which corresponds to the transformation of raw data into thematic categories, allowing a description of the relevant characteristics of the content.

The thematic categories found were: functional mobility, bathing, personal hygiene, getting dressed, sexual activity, home establishment and management, shopping, sleep, social participation, work, leisure and COVID-19.

After recognizing the difficulties in carrying out the daily occupations of patients with COPD and their disruption in the pandemic, the essential ideas were understood: the perception of patients with COPD about their daily activities and repercussions of the COVID-19 pandemic on the patient's daily life with COPD.

Results and Discussion

The results were presented together with the discussions arising from the interviews carried out with patients with COPD. From the analysis of the interviews, the themes that stood out

among the speeches emerged and guided the construction of the following essential ideas: the perception of patients with COPD about their daily activities and the repercussions of the COVID-19 pandemic on the daily lives of patients with COPD.

COPD patients' perception of their daily activities

The path to understanding the self-perception of patients with COPD about their occupational performance, based on the process developed in this study, is faced with numerous possibilities, including the perception reported about their daily activities.

The Activities of Daily Living (ADL) performed with difficulty as a result of COPD mentioned by the patients are part of the following categories: functional mobility, bathing, personal hygiene, getting dressed and sexual activity, reflecting on their performance in performing the tasks of daily living and limiting the quality of performance, as explained in the following lines (Table 1).

Table 1. Units of meaning mentioned in the ADL.

Activities of daily living (ADL)	Context of Units of Meaning
Functional mobility	"When I walk, I get tired" (P1)
	"I have difficulty climbing stairs" (P4)
	"Walking up and down stairs is a problem!" (P6)
	"Climbing the stairs is suffocating" (P7)
	"I cannot walk while carrying a bag" (P9)
Bathing	"I have difficulty raising my arms to wash my hair and to lower them to brush my feet" (P1)
	"I take a shower and get tired" (P2)
	"The water from the shower falls on my head and I get short of breath; I get tired when I take a longer bath" (P5)
	"In the bath, I get tired" (P6)
	"I finish bathing already tired" (P7)
	"I can only take baths with the nasal catheter on" (P8)
Personal hygiene	"I finish bathing tired" (P9)
	"I really liked taking care of my nails, using pliers; I cannot bend down anymore to be able to do it; I used to do it myself" (P1)
	"I cannot comb my hair, but with the device (nasal catheter), I am able to do it" (P8)
Getting dressed	"Washing my hair is tiring" (P10)
	"Getting down to wear shoes tires me" (P2)
	"I have difficulty buttoning my bra" (P3)
	"I feel tired when I put on clothes, short of breath" (P5)
	"Wearing tight clothes and buttoning a bra gets me tired" (P9)
Sexual activity	"Putting on shoes is tiring" (P10)
	"My married life dramatically changed; the sexual intercourse part is very difficult for me" (P3)
	"Dating is slow; it has to be calm" (P7)
	"The husband also has his limitations, so it works." (P9)

Source: Research data, 2020.

The official document, *Occupational therapy practice framework: Domain and process*, of the American Occupational Therapy Association, 2020, which describes the structure and domain of occupational therapy practice, points out that activities of daily living (ADL) are part of the occupations domain and describe them as activities oriented towards the care of the patient with their own body, being fundamental for living in the social world, allowing for basic survival and well-being.

COPD patients often experience problems while performing ADLs. Dyspnea is frequently reported as a limiting factor for the performance of occupations. Patients with COPD experience a greater degree of dyspnea during ADL compared to healthy people, even in the early stages of the disease. Performing these activities increases ventilatory demands and induces dynamic hyperinflation in patients with COPD (Vaes et al., 2011; Vaes et al., 2019).

According to the resolution of the Federal Council of Physiotherapy and Occupational Therapy (Brasil, 2006) number 316, of July 19, 2006, it is the exclusive competence of the occupational therapist, within the scope of their work, to assess the individual's functional abilities, prepare the therapeutic-occupational program and carry out the training of functions for the development of performance skills Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL).

Instrumental activities of daily living (IADL) are also part of the human occupation domain and are characterized as activities that support daily life at home and in the community, which require more complex interactions than those used in ADL (American Occupational Therapy Association, 2020).

The IADLs performed with difficulty due to COPD mentioned by the patients are part of the following categories: home establishment and management, and shopping (Table 2).

Table 2. Units of meaning mentioned in the IADL.

Instrumental Activities of Daily Living (IADL)	Context of Units of Meaning
Home establishment and management	"I do not sweep the house anymore" (P1)
	"Difficulty in hanging clothes" (P3)
	"Difficulty sweeping the house" (P6)
	"I hand wash small pieces" (P7)
	"I do not do laundry or sweep the house, because I would have to take everything out of the way" (P8)
Shopping	"I have difficulty sweeping, wiping" (P9)
	"I do not shop alone anymore" (P5)
	"I never go shopping alone; I cannot push the cart" (P7)

Source: Research data, 2020.

In addition to ADL and IADL, other daily activities that are part of the routine of patients with COPD were reported, such as sleep, social participation, work and leisure (Table 3).

Table 3. Units of meaning mentioned in other everyday activities.

Other occupations	Context of Units of Meaning
Sleep	“The cough wakes me up and I take a long time to fall asleep” (P5)
	“I do not sleep well, I feel suffocated” (P7)
Social participation	“I don’t go to my church group anymore; I cannot help with the functions” (P6)
	“After I started using oxygen, I do not go out on the bus anymore, I almost do not go to my family’s house” (P8)
Work	“I used to sell products to help with household bills; I cannot even do that now” (P1)
	“I got sick and retired” (P2)
	“Retired due to COPD, I worked in a garment factory; there was no way to continue” (P5)
Leisure	“I do not go to the beach, I do not go anywhere” (P1)
	“I have difficulty walking, I get tired, gasping for air, out of breath” (P2)
	“I do not have a social life” (P3)
	“I stopped having fun, I do not dance anymore” (P5)

Source: Research data, 2020.

As our actions are influenced by our values, it is essential for the occupational therapist to know the value that patients place on different occupations, considering the meaning of performing these tasks, as well as the difficulties in performing them, allowing to establish intervention priorities, as well as identifying their desired results (Rogers & Holm, 2002).

In this sense, in occupational therapy, when considering the skills and performance patterns and context in the way these occupations are performed and by enabling the involvement of patients with COPD in these significant occupations, in addition to special meaning and value, the performance of these occupations can produce personal, social, economic benefits for the patient, their families and society as a whole.

Repercussions of the COVID-19 pandemic on the daily lives of patients with COPD

The main preventive measure advocated in the COVID-19 pandemic for the spread of the virus is social isolation, which ended up abruptly changing the routine of all people, causing a generalized interruption in occupational life, affecting all age groups or life cycles in all over the world (Hammell, 2020).

Kamalakannan & Chakraborty (2020) point out that the pandemic restricted the performance of occupations and that patients with COPD, considered more vulnerable, were protected from performing their significant occupations.

Below, patients recognize the changes they have undergone in their occupational life and identify the impact of this social restriction on the pandemic.

I suffered emotionally, I had a crying crisis. (P1).

I do not go out at all, I do not go to the pharmacy or the bakery. (P2).

I do things indoors; I just went to the hospital for treatment; now I do not even do that anymore (P3).

It broke my routine (P4).

I am glad there's monitoring by the team's cell phone, because otherwise I do not even know [what would be] (P5).

Before the pandemic, I used to go shopping with my daughter, put things in the cart, but now it is her who does it alone (P6).

I was already grateful because I was part of the Caminhada do Bosque group; now I am more, because I have been receiving all the support by phone and videos; but I dream of going back to participating in activities (P7).

I would like to go to treatment and see my friends on the Caminhada do Bosque; I miss it (P8).

I feel like a caged bird (P9).

The COVID-19 pandemic highlighted the human need for occupation, its complexity, and the effects of occupational disruption and deprivation (Hammell, 2020). Occupational therapists recognize the changes taking place in the way people perform their occupations as a result of the COVID-19 pandemic and will work with patients to develop strategies to facilitate continued access to their occupations (World Federation of Occupational Therapy, 2020).

Therefore, providing COPD patients with sufficiently careful attention is a real challenge. It is our responsibility to maintain and reinforce rigorous monitoring and management of these patients, with the aim of limiting the side effects that could be induced as a result of the lack of such assistance during the pandemic (Deslée et al., 2020).

Many pulmonary rehabilitation programs were suspended during the pandemic to reduce the risk of spread of SARS-CoV-2, in which remote online, video or telephone consultations were introduced. In fact, this was the alternative found and used for the continuity of care for patients with COPD and other pneumopathies followed for treatment in the post pulmonary rehabilitation maintenance program – “A Caminhada do Bosque”, of which the research participants take part.

The Global Initiative for Chronic Obstructive Lung Disease (2021) recognizes the need to develop new approaches to interacting with COPD patients and highlights remote consultations as an excellent tool to minimize the risk of coronavirus transmission as well as avoid isolation and inactivity, highlighting the importance of patients remaining in contact with their friends, family and professionals who assist them by telecommunication to remain active.

The Federal Council of Physiotherapy and Occupational Therapy (Brasil, 2020), through resolution n. 516, of March 20, 2020, regulated teleconsultation and tele monitoring as viable modalities of work, in order to allow the continuity of actions for some population groups assisted by occupational therapists and physiotherapists.

According to Malfitano et al. (2020), occupational therapy has participated in this alternative care, in view of the daily attention of subjects who, in their different ways of living, share the need for social distance imposed by the COVID-19 pandemic.

The occupational therapist is the professional trained to act in the face of the disruption of daily life, and seeks, through their actions, to promote the reorganization of routines, the readaptation of daily activities and the redefinition of meanings in view of the current situation and challenges caused by the COVID-19 pandemic (De-Carlo et al., 2020).

Final Considerations

Based on the understanding of the difficulties of patients with COPD in performing their daily occupations, taking into account their own experiences in the most diverse situations that are part of their daily lives, it was possible to know how much COPD affects occupational performance and interferes in the most diverse occupations that bring meaning and purpose to life. With the exception of education and playing, all other categories that are part of the occupation domain were mentioned in the study. In addition to the ADLs identified - functional mobility, bathing, personal hygiene, getting dressed and sexual activity - and IADLs – home establishing and management and shopping -, other occupations were highlighted, such as sleep, work, social participation and leisure.

The occupations of patients already limited by COPD were even more impacted by the restrictive measures caused by COVID-19. Offering supervised care through remote care can be an excellent resource used by occupational therapists to help COPD patients overcome their difficulties and limitations during this period of pandemic.

It is expected that further studies be encouraged to be carried out with a focus on relational and subjective aspects, from the patients' points of view in relation to their limitations in performing their daily activities as a result of COPD.

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Roberta Fontenele de Vasconcelos: Collection, organization, transcription and analysis of interviews. Marília Ximenes Freitas Frota: Orientation and textual revision. Valéria Barroso de Albuquerque: Final critical review. Marilene Calderaro da Silva Munguba: Final critical review. All authors approved the final version of the text.

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