

## SIGNIFICADO DE SER CUIDADOR DE PESSOA COM OXIGENOTERAPIA DOMICILIAR: GROUNDED THEORY

## MEANING OF BEING A CAREGIVER OF A PERSON WITH HOME OXYGEN THERAPY: GROUNDED THEORY

## SIGNIFICADO DE SER UN CUIDADOR DE PERSONA CON TERAPIA DE OXÍGENO EN CASA: GROUNDED THEORY

Oyara de Castro<sup>1</sup>, Rogério Silva Lima<sup>2</sup>, Roberta Seron Sanches<sup>3</sup>, Eliza Maria Rezende Dázio<sup>4</sup>, Roberta Garcia Gomes<sup>5</sup>, Silvana Maria Coelho Leite Fava<sup>6</sup>

### RESUMO

**Objetivo:** compreender o significado de ser cuidador familiar de pessoa com doença pulmonar obstrutiva crônica (DPOC) dependente de oxigenoterapia domiciliar. **Método:** pesquisa qualitativa fundamentada nos conceitos e pressupostos do Interacionismo Simbólico e da Teoria Fundamentada nos Dados, desenvolvida em domicílio de 20 cuidadores familiares de um município ao Sul de Minas Gerais, por meio de entrevista, observação participante e elaboração de memorando. **Resultados:** foram construídas as categorias "Se descobrindo como cuidador" e "Mudando a situação de vida em função do papel de cuidador" que resultou deste processo o modelo teórico Ressignificando a vida e o papel de cuidador. Dadas as modificações na vida do cuidador e as atribuições inerentes a essa função, a pessoa busca por novos significados que lhe permitem dar um novo sentido à sua existência. **Conclusões:** o modelo teórico construído representa o significado de ser cuidador familiar de pessoa com DPOC dependente de oxigenoterapia domiciliar sob categoria central que integrou todas as outras categorias. Este modelo permitiu um entendimento amplo do fenômeno estudado, com base nas perspectivas do próprio cuidador e no contexto no qual ele se insere. **Descritores:** Cuidadores; Pneumopatias; Oxigenoterapia; Assistência domiciliar; Enfermagem.

### ABSTRACT

**Objective:** to understand the meaning of being a family caregiver of a person with chronic obstructive pulmonary disease dependent on home oxygen therapy. **Method:** it is a qualitative research based on the concepts and assumptions of Symbolic Interactionism and Data-Based Theory, developed at the home of 20 family caregivers in a municipality in the south of Minas Gerais, Brazil, using interviews, participant observation and drafting of a memorandum. **Results:** From the analysis, the categories "Discovering yourself as a caregiver" and "Changing the situation of life according to the role of caregiver"; the theoretical model signifying life and the role of caregiver was resulted from this process. Given the changes in the caregiver's life and the attributions inherent to this role, the person seeks new meanings that allow him or her to give a new meaning to his existence. **Conclusions:** The constructed theoretical model represents the meaning of being a family caregiver of a person coping with chronic obstructive pulmonary disease (COPD) dependent on home oxygen therapy under a central category that integrated all other categories. This model allowed a broad understanding of the studied phenomenon from the perspectives of the caregiver and in the context in which he or she is inserted.

**Descriptors:** Caregivers; Lung Diseases; Oxygen Inhalation Therapy; Home Nursing; Nursing.

### RESUMEN

**Objetivo:** Entender el significado de ser un cuidador familiar de una persona con enfermedad pulmonar obstructiva crónica dependiente de la oxigenoterapia en el hogar. **Método:** Investigación cualitativa basada en los conceptos y supuestos del Interaccionismo Simbólico y Teoría Basada en Datos, desarrollado en el hogar de 20 cuidadores familiares en un municipio al sur de Minas Gerais, a través de entrevistas, observación de los participantes y redacción de un memorándum. **Resultados:** A partir del análisis, las categorías "Descubrirse como cuidador" y "Cambiar la situación de la vida según el papel del cuidador" que resultaron de este proceso el modelo teórico "Resignificante de la vida y el papel del cuidador". **Discusión:** Dados los cambios en la vida del cuidador y las atribuciones inherentes a este papel, la persona busca nuevos significados que le permitan dar un nuevo significado a su existencia. **Conclusiones:** El modelo teórico construido representa el significado de ser un cuidador familiar de una persona con EPOC dependiente de la oxigenoterapia casera bajo una categoría central que integró todas las demás categorías. El modelo permitió una amplia comprensión del fenómeno estudiado desde las perspectivas del propio cuidador y en el contexto en el que se inserta.

**Descriptor:** Cuidadores; Enfermedades Pulmonares; Terapia por Inhalación de Oxígeno; Atención Domiciliar de Salud; Enfermería.

<sup>1</sup>Mestre em Enfermagem. Docente da Escola de Enfermagem Wenceslau Brás de Itajubá. <sup>2</sup>Doutor. Docente da Escola de Enfermagem da Universidade Federal de Alfenas-MG. <sup>3</sup>Doutor. Docente da Escola de Enfermagem e do Programa de Pós-graduação em Enfermagem da Universidade Federal de Alfenas-MG. <sup>4</sup>Doutora. Docente da Escola de Enfermagem e do Programa de Pós-graduação em Enfermagem da Universidade Federal de Alfenas-MG. <sup>5</sup>Mestre em Enfermagem. Enfermeira da Escola de Enfermagem da Universidade Federal de Alfenas-MG. <sup>6</sup>Doutora. Docente da Escola de Enfermagem e do Programa de Pós-graduação em Enfermagem da Universidade Federal de Alfenas-MG

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## INTRODUCTION

The Chronic Obstructive Pulmonary Disease (COPD) is progressive and has systemic repercussions<sup>(1)</sup>. People living with this disease may have different degrees of dependence due to complications and limitations imposed on them by the illness process. Dyspnea, a cardinal symptom of this morbidity, imposes modifications in the lifestyle, limitations in the activities of leisure and lost in work activities<sup>(2)</sup>. Thus, due to the limitations, in the activities of the household, sometimes people with COPD may need the assistance of their informal caregivers, such as family members<sup>(3)</sup>.

In this context, informal caregivers who, in general, are people of the family, are responsible for caring, with no training, no remuneration, noworker bond<sup>(4)</sup>. In addition, their life is also influenced and changed<sup>(2)</sup>. The caregivers may feel overwhelmed, prioritizing the needs of their sick family member and raising a second plan for their own, including their health. They can usually present comorbidities such as obesity, hypertension, undiagnosed COPD, in addition to symptoms of anxiety and fatigue<sup>(3)</sup>.

This range reflects the importance of health care professionals expanding the emergencies of informal caregivers of people with COPD. It is understood that, in order to be able to propose expanded care actions, which, in fact, meet demands; it is necessary to understand the interactions that caregivers establish in the daily care routine.

In this sense, studies that highlight interactions, such as the central aspects of nursing practice and favor the production of new knowledge<sup>(5)</sup> can contribute to help patients.

In this scenario, the following question arises: who is responsible for the information that is responsible for the health of an individual with COPD because of oxygen therapy at home?

The purpose of the investigation was to understand the meanings of the informal care experience with the COPD oxygen therapy at home.

## METHOD

It is an analytical study, with a qualitative approach, based on Symbolic Interactionism<sup>(6)</sup>. For methodological reference, the Theory of Fundamental Data (TFD) was chosen<sup>(7)</sup>.

It is understood that the assumptions of Symbolic Interactionism can contribute for the better understanding of the phenomenon, since

the family care is a dynamic process; it is modified continuously, as there is interaction between the caregiver and the ill person, they attributed meaning to their actions<sup>(6,8)</sup>.

It is assumed that the actions of the caregiver are significant for both him and his family, thus establishing the conditions possible for a symbolic interaction, producer of actions and behaviors that can only be accessed from an analysis that considers the process of shared construction of meanings.

The participants were selected for convenience. People with COPD were sought, enrolled in the Home Oxygen Therapy Service (SOD) of a municipality in Minas Gerais, who met the following criteria: being a family caregiver of a person with COPD dependent on oxygen therapy, exercising the role of family caregiver, for at least six months, being a resident of the municipality; being 18 years-old or older. Of the 25 caregivers registered, 20 participated in this study, two refused, and three did not meet the eligibility criteria.

The criteria that care for this function has been established for the past six months, as a consequence that the person need the least amount of time to witness a situation experienced<sup>(9)</sup>.

The data were collected in 2016, at home, through open interviews, pre-scheduled audio recordings, participant observation and the elaboration of memorandums, elements of the TFD<sup>(7)</sup>.

The approach of the participants occurs at home and, in the first contact, the objective of the research was explained, as well as the invitation to participate was made. It is noteworthy that in the first interview the family members indicated that they dedicated the longest time to the care of the sick person.

On average, three interviews were carried out with each participant lasting 30 to 60 minutes; it was enough to reach theoretical saturation and the construction of the theoretical model, as determined by the PDT<sup>(7)</sup>. The interviews were conducted by the main researcher who estimated, at the time of the interview, only the presence of the researcher and the participant. A script was used with questions about the social and cultural characteristics of the participants: name, age, education, religious belief, current and previous occupation, family and personal income, marital status, number of children, degree of kinship with

the sick person and time in which he is the caregiver. The guiding question was: how do you feel being the caregiver of a person with lung disease who needs to use oxygen at home? As the data were transcribed and analyzed, new questions were added in order to understand the phenomenon <sup>(7)</sup>.

The data were analyzed by the researchers with experience in the adopted framework, concurrently with the collection and obeyed the three stages of codification. In open coding, the data were transcribed, words and phrases were examined and the first codes were extracted. The process of comparing the data was initiated in order to seek similarities and conceptual differences that constituted the temporary categories. Subsequently, axial coding was carried out, in which the relationship between categories and their subcategories was established, in order to get closer to the phenomenon studied. Memoranda and diagrams containing the analysis products were used. In the last stage, selective coding, the central category that integrated all the others was defined. From this process, the theoretical model that represents the central theme of the study was built. For its validation, it was presented to three participants, with longer experience as caregivers, who were able to recognize themselves in the exposed model. In basing this investigation, in the framework of Symbolic Interactionism, the assumption was followed that the caregiver's actions are significant for both him and his family, thus establishing the possible

conditions for a symbolic interaction, producing actions and behaviors, which can only be accessed, based on an analysis that does not disregard the process of shared construction of meanings.

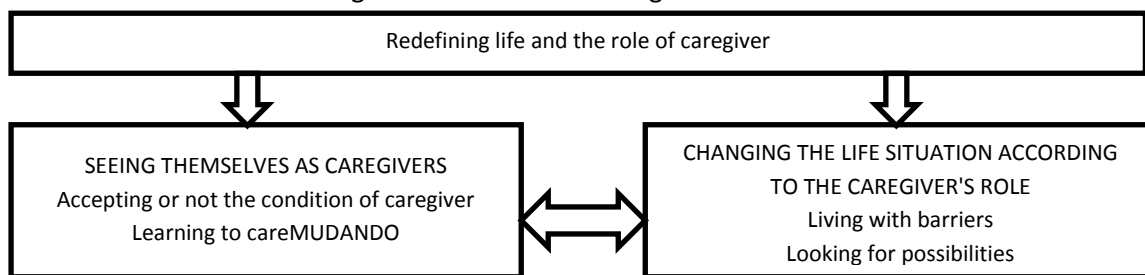
The study was approved by the Ethics and Research Committee of Federal University of Alfenas under Opinion nº 1.092.501. The participants were informed about the research objectives and gave their consent by signing the Free and Informed Consent Form (ICF). Anonymity, confidentiality and their names were replaced with fictitious names.

**RESULTS AND DISCUSSION**

About the 20 participants, 17 are women and three men, with a predominance of the 40-59 year-old age group, with high school, Catholics, married and with children. As for the previous and current occupation, the household predominated, followed by the profession of Professor and Diarist, with a family income of two minimum wages (the current minimum wage was considered to be R\$ 880.00) and no personal income. Regarding kinship with the patient, there was a predominance of children who took care, followed by wives, brothers, grandchildren and nephews. The time with the caregiver ranged from seven months to ten years.

The conceptual model resulting from the analysis could be represented by the central category: Redefining the life and role of caregiver and the categories and subcategories, as shown in Figure 1.

Figure1-Theoretical Model: Redefining life and the role of caregiver



Source:it was created by the authors

**Seeing themselves as caregivers**

It was possible to apprehend that the caregiver discovers himself/herself in this work, and, based on this discovery, builds meaning to this function, however she/he is not always able to clearly discern the moment when he started to assume care. Generally, this fact occurs involuntarily due to the circumstances of the

disease, since the patient is in a fragile and vulnerable state. Some elements favored the person taking the care action, such as: being a woman, geographic proximity and financial dependence. “[...] Since I got divorced from my partner, I came to live with my mother, because I had nowhere to go and, when she became ill, I became her caregiver, because I don't work, my

brother works all day [...] "(Paula, 52 years-old). "[...] When my husband and father died, I had to come and take care of her, because, as I am a woman, it always ends up that we have to take care of [...]" (Leticia, 58 years old).

Although there are a higher number of women as caregivers, some men took on this job, due to the lack of someone to perform such an activity. "[...] caring her is challenging, it is special, she is everything for me and she is still alive, but while she is here with me, I will be careful with her, taking care of her because tomorrow she may not be alive anymore, I think that everyone who goes through a similar situation should stop to really think, it is better to have her here with me than anywhere else [...], (Lúcio, 38 years-old)."

The process of accepting the role of caregiver does not always occur easily and spontaneously. The caregiver, faced with the need to care for his family member, experiences many dilemmas. As it is an arduous task, the caregiver demonstrates difficulty in accepting a situation that is not temporary and seems to last throughout the patient's life. "[...] I do not accept the situation he has faced nowadays, I have my hands tied and this is the end of the world, I take care of him, but it is very difficult for me [...]" (Luana, 54 years-old).

Learning how to take care of a family member is a task permeated by successes and mistakes, since the family caregiver is unaware of the disease and has no preparation that enables him to exercise it, making him learn to care, based on the observation and interpretation of manifestations. "[...] for seeing her when she is so sick, now I even know when things are going to get complicated. She starts to pull the air to try to breathe and soon her mouth turns purple, I feel sad to see her in this situation. She says that her mouth is dry and she feels that she is going to die. Sometimes, just by adding oxygen, she gets better, at other times, I have to take her to the hospital [...]" (Amanda, 53 years-old).

It is noticed that the caregiver does not usually understand the disease. He knows that is a matter that affects the lungs functions, which restrict the family member's daily activities and require dependence on home oxygen therapy to survive. Initially, the experience with oxygen therapy generates fear and insecurity for the caregiver, as he fears that some problem may happen with the oxygen concentrator. "[...] when my husband started using the oxygen device, it

was very complicated, because I had to keep watch over all the time and I didn't know what to do if something happened. He who helped me watch if I was everything is right [...]" (Ana, 80 years-old).

The situation due to the role of caregiver is changed.

There are many barriers that the caregiver has to face daily, making himself weakened and vulnerable by constant stress and tension. The caregiver realizes that taking care requires time and dedication and that sometimes his needs cannot be met, as he understands that the patient's demands must be prioritized. "[...] it was a long time since I was feeling pain in my knees, but I didn't have time to go to the doctor until I started limping and feeling pain. He said it is osteoarthritis and that I can't stay in the day all day. [...]" (Claudia, 81 years-old).

Changes in her life are observed, such as the compromise of married life can lead the caregiver to show intense emotional suffering. "[...] It is difficult to be away from my husband, to live in a different city from him to be with my grandmother. Although my husband gives me the greatest support, I am afraid he will not be able to endure this situation and ask for separation. I am very sad, but I am also divided by this situation [...]" (Raquel, 38 years-old).

Difficulties are also manifested in basic questions of household chores and personal life. The fact that the sick person cannot be alone at home and the lack of support from other family members contribute so that the caregiver realizes that he can no longer control his own life, which corroborates his social isolation. "[...] I always liked to go out, to go to the bar with my friends, but now it's difficult, because every time when I want or need to go out, I have to find someone to stay with my mother and, even if I do, the head stays always stressed, because I don't know what's going on here at home. I even go out from time to time, but it's not like it used to be [...]" (Leticia, 58 years old).

In addition to the aspects mentioned, the additional cost of electricity was also a factor that generates stress, as it constitutes an increase in expenditure on the reduced family income. "[...] the electricity bill became very expensive, after that she started using oxygen all the time. I already tried to get a discount at Cemig (electric power company from Minas Gerais) and it doesn't work, and I keep wasting time going there at Cemig [...]" (Marina, 25 years-old).

To adapt to the new situation, the caregiver seeks strategies, such as support from neighbors and religion. [...] My neighbor is like someone from my family. I can count on her for everything she helps me [...] "(Cláudia, 81 years-old)" [...] Taking care of him is something that it comes from God, he gives me strength, because if it were mine, it would be very difficult, so today we live well [...] "(Sara, 41 years-old).

From this analysis, according to the proposed framework, it is learned that taking care of the patient with COPD requires restructuring the dynamics of the family caregiver's life, considering that it is a person from the family who takes responsibility for the care of their patient. In view of the limitations caused by the disease, he does not receive remuneration for his services<sup>(10-11)</sup>.

The results show that the majority of people who assume the role of family caregiver are women, in line with the literature<sup>(10-13)</sup>, because women are expected to take care of the sick, as an extension of their maternal function. It also brings an important contribution when identifying the man with the caregiver. Although the majority is in an age group, economically productive, they have no previous or subsequent employment relationship, when they assume the role of caregiver of their relative, showing financial dependence. However, the care provided by informal caregivers can have benefits, such as an increase in the bond with the person being cared for and a great economic value, for reducing the costs of care, when compared to the costs of the hospitalized person<sup>(10,14)</sup>.

Other factors may have contributed to someone becoming a caregiver, such as the bond, proximity, co-residence with the sick person, unfavorable financial conditions, lack of employment and marital separation<sup>(11)</sup>.

COPD is considered a limiting pathology that increases the patient's dependence and forces him to use devices, for respiratory support that the family caregiver is not prepared to deal with, increasing the difficulties to perform the care<sup>(15)</sup>.

It was observed that the caregiver is obliged to deal with objective elements (oxygen concentrator and all its accessories) and subjective ones (conceptions about COPD and relationships established with the care activity), related to the new role it plays. The activities carried out by the caregiver in daily life lead him

to dedicate more and more time to the sick person, creating overload, deprivation, social isolation and financial difficulties that are situations that generate stress and bring intense anguish, impotence and hopelessness, in relation to the patient, and can cause serious health problems to the caregiver's life<sup>(16)</sup>.

A study carried out with caregivers who live with their families and use the oxygen concentrator, pointed out that they have the feeling that the device has invaded their home, as they find themselves surrounded by wires and the noise that is disturbing during sleep<sup>(15)</sup>.

It appears that the process of reorganizing the roles of the family caregiver does not take place in a calm and natural way, since it is not planned or chosen<sup>(17)</sup> and, generally, it begins with the decrease or inability of the person who fell ill to provide their own care<sup>(18)</sup>.

The condition of caregiver awakens a mixture of negative and positive feelings related to the fact that care becomes increasingly complex due to the severity of symptoms, the loss of independence of the patient and the affection between them<sup>(19)</sup>. It is understood, therefore, that the process of accepting the role of caregiver is complex and intrinsically related to the elaboration of meanings established in the interaction. It is in this experience that the caregiver feels the importance of caring and is not prepared to deal with this condition<sup>(20)</sup>.

In this process, the caregiver can decode this role of interpreting the symptoms presented by the patient and of assessing the need or not for oxygen administration, which can contribute to making them feel more confident and safe, as they are able to properly care for their family members<sup>(20)</sup>. This process is dynamic, given that the attribution of meanings and changes in the interaction<sup>(6,8)</sup>.

This factor is relevant when one considers that the family caregiver of people with disabling diseases is more affected than other caregivers<sup>(10-11,13)</sup>, which corroborates the significant increase in the level of stress due to the pertinent care responsibilities.

In the case of COPD, as it is a chronic and disabling condition, it affects both the life of the patient and the life of his family caregiver, as he daily experiences the worsening of symptoms, the restrictions and the reluctance of the patient to use oxygen according to medical guidelines. This situation increasingly imposes greater dependence on the sick and, consequently,

greater burden on the caregiver, which demands emotional, practical and informative support from health professionals<sup>(21)</sup>.

Therefore, the experience of being a caregiver is marked by suffering, as a result of the family member's illness and the problematic situations that involve care.

The difficulty to take care of their own health, also, emerges with the problem, due to lack of time, especially when they are the only ones responsible for the care, which compromises their well-being and exposes them to constant risk of illness<sup>(3, 22)</sup>. The caregiver realizes that dedicating himself fully to the task of caring prevents him from carrying out activities that he practiced before, which brings losses to his family and conjugal life<sup>(22)</sup>. This situation is further aggravated by the lack of support from the family, which compromises quality of care provided and the life of the caregiver who is sometimes alone<sup>(20)</sup>.

Although they have to live with countless barriers, caregivers were able to seek strategies that allowed them to deal with adverse situations in order to face their daily care routine for the sick and relieve stress<sup>(23)</sup>. Coping strategies represent concrete possibilities for the caregiver who needs to reduce the burden, so that his life has more quality<sup>(24)</sup>.

Faith emerges as a source of energy and hope for maintaining emotional balance, promoting well-being and improving the quality of life, by feeling well comforted and strengthened, since it is a way of experiencing your connection with the self, with others and with the Sacred<sup>(25)</sup> and thus reduce the negative feelings of the task of caring<sup>(11)</sup>.

It is learned that the caregiver, in view of the complexity of care, requires the mobilization of multiple knowledge and practices, becoming, from these experiences, more tolerant, patient and more humane people. This experience brings the caregiver possibilities to reframe the demands of his new role.

## CONCLUSIONS

Being an informal caregiver for people with COPD is having life changed in function of those who need to be cared for, living in a context that is not always favorable, as it is marked by illness, dilemmas, suffering and restrictions. Paradoxically, positive aspects are opposed, related to coping strategies, such as the support of family and religion, showing that they

are capable of becoming sensitive and offering care to the sick family member, as well as the attribution of a new meaning to this experience. The cross-sectional and outdated registration of people with COPD can be considered limitations of this study. However, the theoretical model constructed is in line with the literature.

For nursing, the understanding of this process brings contributions, because it allows an expanded look at the needs of the caregiver and the importance of implementing programs to serve them from the perspective of comprehensiveness.

Studies are needed to analyze strategies to support informal caregivers of people with chronic conditions in the process of adapting to this role.

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**Mailing address:**

Silvana Maria Coelho Leite Fava  
R. Gabriel Monteiro da Silva, 700- Centro  
Alfenas-MG, Brazil.  
CEP: 371130-001  
silvana.fava@unifal-mg.edu.br