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Caring for elderly people during the COVID-19 pandemic: the experience of family caregivers

Cuidar de idosos durante a pandemia da COVID-19: a experiência de cuidadores familiares

El cuidado de los ancianos durante la pandemia del COVID-19: la experiencia de los cuidadores familiares

Cristiane de Paula Rezende[a,b]
Mariana Martins Gonzaga do Nascimento[a,b,c]
Amanda Patricia de França[b]
Aline Silva de Assis Santos[a,b]
Isabela Viana Oliveira[a,b]
Djenane Ramalho de Oliveira[a,b,d]

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ABSTRACT

Objective: To build a theoretical model that represents the experience of family caregivers of elderly people during the COVID-19 pandemic.

Method: Qualitative study that used the Grounded Theory as a methodology, carried out in Minas Gerais State in August 2020. 16 caregivers were interviewed.

Results: Uncomfortable emotions emerged and drove the caregivers' actions to: adopt preventive measures to protect the elderly from contracting the coronavirus; guarantee their healthcare; and make them aware of the pandemic. However, when these emotions manifested in an exacerbated manner, they needed to be alleviated so that they could adopt such initiatives.

Conclusion: The emotions felt by caregivers can compromise their health and quality of life. Therefore, health professionals need to create strategies to ensure that they are well assisted, enabling care through telehealth. Guidance on the pandemic for caregivers could reflect better care for the elderly people.

Keywords: Caregivers. Aged. Grounded theory. COVID-19. SARS-CoV-2. Home nursing.

RESUMO

Objetivo: Construir um modelo teórico que representa a experiência de cuidadores familiares de idosos durante a pandemia da COVID-19.

Método: Estudo qualitativo que utilizou como metodologia a Teoria Fundamentada nos Dados, realizado em Minas Gerais em agosto de 2020. Foram entrevistadas 16 cuidadoras.

Resultados: Emoções desconfortantes emergiram e impulsionaram as ações das cuidadoras em prol de: adotar medidas preventivas para proteger os idosos de contraírem o coronavírus; garantir a assistência à saúde do mesmo; e, conscientizá-lo sobre a pandemia. Todavia, quando essas emoções se manifestavam de formas exacerbadas, elas precisaram ser amenizadas para que elas conseguissem adotar tais iniciativas.

Conclusão: As emoções sentidas pelas cuidadoras podem comprometer sua saúde e qualidade de vida. Portanto, os profissionais de saúde precisam criar estratégias para garantir que elas estejam bem assistidas, viabilizando atendimentos por meio de telessaúde. A orientação sobre a pandemia aos cuidadores poderá refletir em um melhor cuidado aos idosos.

Palavras-chaves: Cuidadores. Idoso. Teoria fundamentada. COVID-19. SARS-CoV-2. Assistência domiciliar.

RESUMEN

Objetivo: Construir un modelo teórico que represente la experiencia de los cuidadores familiares de ancianos durante la pandemia de COVID-19.

Método: Estudio cualitativo que utilizó como metodología la Teoría Fundamentada, realizado en el estado de Minas Gerais en agosto de 2020. Se entrevistó a 16 cuidadores.

Resultados: Surgieron emociones incómodas que impulsaron las acciones de los cuidadores para: adoptar medidas preventivas para proteger a las personas mayores de contraer el coronavirus; asegurar la asistencia sanitaria para los mismos; y hágale saber sobre la pandemia. Sin embargo, cuando estas emociones se manifestaban de manera exacerbada, era necesario aliviarlas para que pudieran adoptar tales iniciativas.

Conclusión: Las emociones que sienten los cuidadores pueden comprometer su salud y calidad de vida. Por lo tanto, los profesionales de la salud deben crear estrategias para garantizar que los cuidadores estén bien atendidos, posibilitando la atención a través de la telesalud. La orientación sobre la pandemia a los cuidadores puede reflejar una mejor atención a las personas mayores.

Palabras clave: Cuidadores. Anciano. Teoría fundamentada. COVID-19. SARS-CoV-2. Atención domiciliaria de salud.

[a] Universidade Federal de Minas Gerais (UFMG), Faculdade de Farmácia, Programa de Pós-Graduação em Medicamentos e Assistência Farmacêutica. Belo Horizonte, Minas Gerais, Brasil.

[b] Universidade Federal de Minas Gerais (UFMG), Faculdade de Farmácia, Centro de Estudos em Atenção Farmacêutica. Belo Horizonte, Minas Gerais, Brasil.

[c] Universidade Federal de Minas Gerais(UFMG), Faculdade de Farmácia, Departamento de Produtos Farmacêuticos. Belo Horizonte, Minas Gerais, Brasil.

[d] Universidade Federal de Minas Gerais(UFMG), Faculdade de Farmácia, Departamento de Farmácia Social. Belo Horizonte, Minas Gerais, Brasil.

INTRODUCTION

The accelerated aging process in Brazil presents a big challenge for society and for health systems, since a considerable part of the elderly at an advanced age has chronic and disabling health problems, leading to greater dependence and requiring long-term care[1–3]. Data from the National Health Survey (PNS-2013) showed that about 30% of Brazilians aged 60 years or older have some difficulty performing at least one of the ten activities listed as activities of daily living[2]. In line with these findings, the results of the Brazilian Longitudinal Study of Aging (ELSI-Brasil) revealed that approximately a quarter of Brazilians aged 50 years or more reported having some type of difficulty in performing activities of daily living, and among those who received help from third parties, 94.1% reported that care was provided by family members, especially women (72.1%). The ELSI-Brasil is a cohort study with a representative sample of the Brazilian population aged 50 years old or more. The baseline was conducted between 2015 and 2016[2].

Traditionally, when the elderly person needs long-term care, it is provided by relatives, friends, neighbors or, to a lesser extent, paid caregivers. As a result, it is necessary to consider the caregiver's health and their experience in caring, since they have become a key element in providing home care for the elderly, and their health status influences the quality of care provided[1–3].

Family caregivers are those individuals who provide care to the elderly who have some degree of dependence, for prolonged periods, usually until their death. These individuals assume the responsibility of offering the support that the elderly person needs, either ensuring basic care, such as food and hygiene, or helping the elderly person in other activities, such as shopping and performing financial tasks[4].

In this context, it is important to highlight that the experience of caregivers, when caring for elderly relatives, suffers from situations of conflicts, tensions, physical and emotional exhaustion, social isolation and work overload, which can cause the appearance of health problems and the need for medication use[1–4]. This circumstance can be aggravated by the emergence of the new coronavirus, which causes the Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2) called Corona Disease 2019 (COVID-19), since both the elderly and caregivers could be contaminated by the disease.

The new coronavirus was first identified in the city of Wuhan, China, in December 2019, and since then it has spread worldwide. In Brazil, the first case was confirmed on February 26, 2020 and the first wave of cases mainly affected elderly Brazilians with comorbidities[5–7]. COVID-19 was characterized as a pandemic by the World Health Organization (WHO) and represents a threat to society and global health systems[6].

In view of this scenario, the following question emerges: how are family caregivers experiencing caring for the elderly during the COVID-19 pandemic? Understanding the experience of caregivers in this pandemic scenario is important to support actions that guarantee support for these individuals during the coronavirus pandemic or in other moments of health uncertainties, as well as guide health professionals during health care for both the elderly and the caregiver. Therefore, the present study aimed to build a theoretical model that represents the experience of family caregivers of the elderly during the COVID-19 pandemic.

METHOD

The present qualitative study used the grounded theory as a methodology, according to the assumptions presented by Kathy Charmaz[8]. Following the epistemology of subjectivism, Charmaz positions herself in the paradigm of social constructionism and is based on the symbolic interactionist theoretical perspective, signaling that the research process emerges from the interaction between the researcher and the researched[8]. In addition, data and theory are not discovered by themselves, they are influenced by the world in which they were studied and collected[8].

Therefore, this research used symbolic interactionism as a theoretical framework. This theory was relevant for understanding the phenomenon studied, since the experience of care is permeated by the reciprocal and dynamic social interaction between the caregiver and the care receiver, and such interaction is also being influenced by the pandemic situation.

In view of this, the grounded theory allowed us to understand how caregivers of the elderly are experiencing their care routine during the pandemic. Additionally, from the relationship between the categories constructed, it was possible to build a theoretical model that represents such experience.

Participants in this study were people who consider themselves family caregivers, who were caring for an elderly person during the SARS-CoV-2 pandemic period, and who resided in the state of Minas Gerais, Brazil, at the time of the first contact and interview.

The state of Minas Gerais has a population of approximately 21 million inhabitants, of which 5.17% are over 65 years old. The state aging index shows that the proportion of elderly people from 2020 to 2060 will increase from 56.47 to 217.14. Currently, in addition to the primary and secondary

health care network, Minas Gerais has the More Life Centers (*Centros Mais Vida*) and the State Specialized Care Centers (*Centros Estaduais de Atenção Especializada* – CEAE), which provide multiprofessional care to the geriatric population[9].

For the recruitment of participants, in view of the pandemic situation, a digital poster was elaborated, which was disseminated on social media (Facebook®, Instagram® and WhatsApp®) during the period of data collection and analysis. The poster invited family caregivers to participate in the research and share their experiences in caring for an elderly relative. The material also contained the identification of the research and researcher and forms of contact, so that interested people could participate. People who knew a family caregiver for the elderly also contacted him, sharing information about the research. Caregivers who cared for an elderly relative in the home environment and who considered themselves the main caregivers were included.

Caregivers who made contact by identifying themselves with the research call were invited to participate. In case of acceptance of the invitation, individual interviews were scheduled on the day and time preferred by the participants. The ordering of the participants for the sampling occurred as those interested in responding were available to participate.

Although there is no gender criterion for the inclusion of participants, the sample was composed entirely of female caregivers. The names of the participants were replaced by fictitious names defined by the authors, to ensure anonymity.

All participants formally consented to their participation by physically signing the Free and Informed Consent Form (FICF). The FICF was scanned and sent by e-mail. Data collection and analysis took place during the month of August 2020. People interested in participating who were experiencing the phenomenon of caring for an elderly relative were interviewed via video call using their preferred software.

According to Charmaz, interviews are focused and intense conversations that allow for a deep discussion on a specific theme with people who have relevant experiences on the subject[8]. The interviews were conducted in two stages.

In the first stage, a semi-structured questionnaire was used, containing information about individual sociodemographic characteristics, as well as the degree of kinship with the elderly. The age and degree of dependence of the care receiver were also asked. For this, the people interviewed answered – according to their perception – if the care receivers had any cognitive deficit and/or if they were able to perform the following activities: managing their finances, going to distant places and using public transport or driving, shopping, preparing meals, do household tasks, manage medication use, use the telephone, bathe, dress, take care of personal hygiene, transfer, control urine and feces, eat. Such questioning was performed in order to understand the level of care demand that the elderly required from the perspective of caregivers.

In the next stage, the semi-structured interview was applied, seeking to understand the phenomenon of caring for an elderly person during the COVID-19 pandemic from the perspective of the person interviewed. For this, a guide topic was elaborated to guide the interviews, which initially contained the following questions: How was going the care routine during the pandemic? How did the people interviewed feel about providing care to their elderly relative during the pandemic? What were the difficulties in the care routine in the pandemic scenario? What were the strategies that the people interviewed were adopting to be able to deal with this new reality of caring for an elderly person during the coronavirus pandemic?

The grounded theory makes it possible to extract data from several sources[10]. Thus, the answers to the questions addressed in the semi-structured questionnaire mentioned above were used to better understand the phenomenon. In addition, the questions present in the guide topic were modified, discarded, or replaced throughout the interviews to provide important information that would contribute to the data analysis and the construction of categories and concepts.

The interviews lasted approximately 41 minutes, ranging from 23 to 60 minutes. For data analysis, not only the transcripts of the interviews were used, but also the notes made in the field diary. These notes allowed the recording of impressions, as well as non-verbal behaviors of the participants.

In grounded theory, the sampling process aims to build a theory. Data collection began with the interview of a granddaughter who took care of her grandmother. Based on the initial analysis of this interview, new data were collected to deepen the research problem and commitment to the construction of categories[8,11].

To compose the theoretical sampling, interviews were carried out that could provide new insights for understanding the phenomenon. The selection of the other participants for the theoretical sampling was conducted based on the development of the research, seeking to include people who provided care to elderly people with different levels of dependence according to their perspective.

Constant comparisons between the data were performed until a repetition of the responses was observed, characterizing saturation, that is, when the collection of new data did not reveal new concepts or new properties of the categories or central themes[8]. Thus, respecting the data saturation

process, interviews were conducted with 16 caregivers. The audios of the interviews were recorded in the OBS Studio software and fully transcribed for data analysis. To assist in this process, the NVivo 10 software was used.

The grounded theory methodology is not linear, since the phenomena are discovered, conceptually developed and verified by a process of data collection and analysis simultaneously conducted. The analysis began right after the first interview, as recommended by grounded theory, through line-by-line coding. This first analysis guided the collection of the next data. Thus, at each new interview, new coding was performed line-by-line, always comparing the data within the same interview and with previous interviews. Next, through focused coding, it was possible to select the most relevant nuclei of meaning to be tested with other broader data and, thus, categorize them in an incisive and complete way. Finally, selective coding was performed, in which the relationship between the categories constructed was determined until reaching the theoretical model[8,11].

There was an analytical pause for the elaboration of memos throughout the process, in order to complement it. The writing of memos leads to reflection on their data, compares, produces connections, crystallizes questions and seeks directions to complete emerging categories from the beginning of the process and throughout the course of the research. Thus, the writing of the memos was fundamental to increase the level of abstraction of the codes, to build categories, and to assist in the construction of the theoretical model[8].

The ethical precepts regarding research involving human beings, established by Resolution No. 466/12, of the National Health Council, were considered. This study was evaluated by the Research Ethics Committee of the *Universidade Federal de Minas Gerais* and approved through the Opinion No.4,173,041.

RESULTS

Sixteen family caregivers were interviewed. Half of them were single or divorced, most of them were daughters (n=13) and the others were: granddaughter (n=1), daughter-in-law (n=1) and sister of the care receiver (n=1). Ten caregivers were over 50 years old and all the elderly were over 75 years old. Among the participants, only one had studied for only four years; the others studied for more than 11 years, nine of them having completed higher education. Fourteen caregivers cared for an elderly relative and two cared for the elderly mother and father simultaneously.

After a systematic analysis of the data, it was built the theoretical model "Caring for the elderly during the COVID-19 pandemic by family caregivers", comprising four main categories.

The first category, called "Becoming aware of the pandemic context", was divided into three subcategories: "Recognizing the elderly as part of the vulnerability group"; "Feeling uncomfortable emotions"; and "Softening emotions: 'because there's no use in despairing'". This category reveals how caregivers, upon becoming aware of the COVID-19 pandemic, initially reacted to this scenario, and realized that they needed to mobilize to prevent the elderly from contracting the coronavirus.

This reaction configured the other categories: "Adopting preventive measures to protect the elderly from contracting the coronavirus"; "Ensuring health care for the elderly during the pandemic"; and "Making the elderly aware of the pandemic".

Becoming aware of the pandemic context

The world society was surprised by the SARS-CoV-2 pandemic. This coronavirus emerged in China and then there were cases and deaths in Europe, which were announced in Brazil, impressing both caregivers and the elderly, as described in the speech:

> [...] *that scene in Italy... she* [the elderly woman] *was impressed with that scene of the trucks carrying a lot of coffins.* (Larimar).

Despite the news reporting that the new coronavirus was spreading all over the world, some caregivers reported that, initially, they did not notice the dimension of the disease, and that they only realized this when drastic events occurred close to them or affected their reality directly, as exemplified in the statements:

> *Out of nowhere, they said there was a guy who had the virus. When you think not, they tell you to stay at home; they ordered to close everything because the disease was taking over. That was panic for me.* (Rubelita).
>
> *A friend of ours died because of the coronavirus. It was horrible to find out that the person died from it. As people say: "we only feel when we have a face".* (Jade).

The following will be presented the three subcategories inserted in this category.

Recognizing the elderly as part of the vulnerability group

With the emergence of COVID-19 cases in Brazil, the media and government authorities highlighted that the elderly were people most vulnerable to this disease. Faced with this, Safira exposed her concern with her parents:

> *In their case are elderly, we have a much greater concern, because their age is a very advanced age:87, 84 years old.* (Safira).

Caregivers also signaled fear, since the elderly are even more vulnerable to COVID-19 due to the presence of chronic diseases:

> *The concern is mainly with them, because, in addition to being elderly, they have heart problems, high blood pressure... So, they are included in practically all risk groups...* (Jade).

In view of this, upon recognizing that the new coronavirus was infecting several people in the world and many of them dying, especially elderly people with comorbidities, caregivers felt concern among other uncomfortable emotions.

Feeling uncomfortable emotions

The uncomfortable emotions translate the caregivers' science of being responsible for the care of individuals who are at greater risk of developing the most severe forms of COVID-19. Safira presented a reflection that illustrates how such a perception brought her discomfort:

> [...] *other things can happen. There are so many people who die every day for so many things. But suddenly you see something threatening. It is complicated! I think everyone is feeling threatened* [...]*, it's a very bad situation; as if you had a sword pointed at your head all the time; you don't know what to do. We have no power; nobody has.* (Safira).

In response to this feeling of threat and impotence, the fear of dealing with death was also expressed:

> *I'm very afraid of that: of dealing with death.* [...] *I'm honestly very afraid of this happening today and I can't do nothing.* (Larimar).

In contrast, Pedra da Lua revealed another perspective of fear:

> [...] *we are afraid of the disease. It is not afraid of death itself, but of suffering. Of this I am afraid.* (Pedra da Lua).

The fear of their own contamination and guilt for transmitting the coronavirus to the elderly also emerged from the caregivers' speech:

> *So, a little afraid* [...] *of me taking it and passing it on to him* [elderly]. *We get that feeling of "wow, if I pass it on to him... if the worst happens, it's my fault".* (Turmalina).

Other negative emotions also emerged, represented in the participants' speech by nouns such as: anguish, impotence, insecurity, dread, panic, horror, worry and sadness. Despite being uncomfortable, all these emotions were essential to generate changes in the care routine, and to encourage caregivers to adopt measures to prevent COVID-19, so that they feel better, as can be seen below:

> *Fear! A lot of fear, a lot of worry. That's why I'm doing everything the Ministry of Health asks; Secretary of Health asks: stay at home, take care of your hands.* (Larimar).

On the other hand, if uncomfortable emotions were experienced in an exacerbated way, they served as a driving force in the opposite direction to the search for prevention of COVID-19, paralyzing the caregiver and compromising her ability to respond to the pandemic. Caregivers in this position reported the need to adopt strategies to soften such feelings.

Softening emotions: "because there's no use in despairing"

Many of the interviewees reported the need to "disconnect" from the pandemic, considering that, if they despaired, they would be unable to react:

> *In fact, I can't worry. If I go for it, I'm going to go crazy. So I try to stay calm. You understand me? I try to do my part in everything. I do feel; but don't despair because there's no use in you despair. If I despair, I won't even be able to work.* (Tanzanita).

When "dispairing", as named by Tanzanita, the caregivers reported that they can compromise not only their care routine, but also their well-being. In this way, the creation of strategies to soften the emotions felt in an exaggerated way is pointed out as fundamental by the interviewees. One of the strategies found in the reports was the need to talk to a health professional who would clarify whether, in fact, the interviewee was exposed to the risk of being contaminated as she imagined:

> *I started to get really desperate. I talked to one of the doctors who was there* [Health Center] *and a social worker. We started talking about the things we were feeling and I think it was good to talk about it.* (Turquesa).

Another important point to soften uncomfortable emotions was obtaining more knowledge about the disease, as well as what actions were necessary for its prevention:

> *I'm calmer now. Because we are already understanding more about the disease; about the virus. We are seeing a lot of information, we are seeing that you have to wear a mask, that you have to use hand sanitiser, soap, wash hands all the time. So, a little [fear] went away, it's now softened.* (Turmalina).

Religious belief and spirituality also emerged as a strategy:

> *I'm terrified of catching this coronavirus. But that's what I told you: my religion, spiritism, clarifies a lot for me.* (Pedra da Lua).
>
> *My concern was more for her. I actually don't despair about anything, because, in addition to believing in God a lot, I'm calmer.* (Tanzanita).

Getting distracted, performing pleasurable activities and getting involved with some interesting projects were some ways that the interviewees adopted to disconnect from what was happening. On the other hand, most caregivers revealed that they avoid watching television, as it is a stressful activity:

> *We try to talk, see other things. But, for example, the whole day on television you only see they talking about it. So, I try to distract, read a book, see nonsense on WhatsApp, see jokes, to get away a little bit.* (Alexandrita).
>
> [...] *if we sit down to watch television, we die. So, I'm avoiding it, because we really get scared.* (Turmalina).

Once aware of the circumstances of the pandemic, the interviewees reported the need to adopt the following initiatives to prevent the elderly from contracting SARS-CoV-2: putting in place preventive measures, ensuring health care for the elderly during the pandemic, and, when possible, make the elderly aware. Such initiatives comprise the categories presented below.

Adopting preventive measures to protect the elderly from contracting the coronavirus

The caregivers revealed that they changed both their routine and the routine of the elderly as a result of the pandemic, as illustrated below:

> [...] *I'm at home exactly because of her.* (Larimar).
>
> [...] *my grandmother doesn't leave the house. Anyone can leave the house but her.* (Rubi).

On the other hand, some of the interviewees – who, according to their perception, took care of elderly people who had difficulties in dressing, transferring, eating, bathing and controlling urine and feces – reported that the routine did not change much:

> *It doesn't change much thing in our routine. It changes like this: we cannot go out; we cannot have contact with people; this hand hygiene. These hygiene care has increased a lot!* [...] *This isolation that is the most complicated. But in the treatment, in the care for her, I don't notice much change, because I already did it naturally.* (Ametista).

Other caregivers revealed that the care provided directly to the elderly remained the same. However, the need arose to adopt some initiatives, which were considered crucial to protect the elderly from the coronavirus, since, at the time of the interviews, there were no vaccines and effective drugs to prevent and treat, respectively, the disease. Therefore, the caregivers put non-pharmacological measures into practice in order to protect the elderly, as illustrated by the statements:

> *We double the cleaning and we are even a little paranoid* [laughs]. (Esmeralda).
>
> *I always wear a mask, washing my hand, unsig hand sanitiser, taking care of cleaning.* (Ametista).
>
> *I arrive at her house, there is all that procedure to enter the house. I sanitize everything and whenever I get closer to her, I keep the mask.* (Turquesa).

In addition to the related care, physical distancing was also adopted as a preventive measure. This initiative was experienced in a peculiar way, according to the level of dependence that the elderly person had from the caregivers' perspective, as can be seen below:

> *It has changed a lot in relation to my father. We don't let my father go outside the street*. [...] *keeping my father in the house, without him being downcast, so in that sadness of not being able to go out, is the most complicated part for me. As for my mother, it didn't make any difference, because she doesn't walk alone. So, she never left the house anyway.* (Caregiver for her dependent father for IADLs and her bedridden mother).

According to the interviewees, the difficulty in ensuring physical distancing stems from the fact that the elderly is used to having children and grandchildren visiting them, going out – even if accompanied – to shop at the supermarket, go to the bank, go to church. Such routine was abruptly changed, affecting care receivers, as can be seen in the statements below:

> *It is a difficult adaptation for everyone, including them* [care receivers], *because no one is coming here. Before, every time there was a grandson, a son; everyone came here. Suddenly, no one comes anymore! Today, for example, my nephews came here and stayed outside.* [...] *They didn't go out alone, but we went to the supermarket every week, we went to church every Saturday. So, they don't go out a little, but suddenly, not being able to go out is complicated.* (Safira).

Caregivers also conveyed how much physical distancing has impacted their lives:

> *It's not good, because it's one more time that I'm alone, because the visits here at home have decreased. So, it's very complicated to be just the three of us here in the house. It is not easy!* (Jade).

It became evident how difficult it is to avoid physical contact with care receivers. To soften the discomfort of not receiving visitors and isolating themselves as a preventive measure, the interviewees started to make video calls to keep in touch with relatives and friends in a safe way. The following speech illustrates this new form of social interaction:

> *We are grabbing our cell phones to get in touch with people, to find out what is happening to them. This improves, because if not, we freak out.* (Jade).

Caregivers also reported that they dismissed people who helped with care, as they understood that, because they lived with other people and used public transport, they were at risk of contracting the coronavirus and transmitting it to the care receiver. They reported that this resulted in an increase in their workload:

> *There's no time left for anything. While she sleeps in the morning – from 10 am to 12 pm – I can clean the breakfast dishes, wash, tidy and sanitize her room, the bathroom that I bathe her.* [...] *I am unfolding. At 8:30 at night, I put her to sleep, and at that moment, I could sit down to watch TV, but I look at the kitchen: "wow, there's so much to do"* [...]. *But that's it: that routine of housewife and caregiver simultaneously.* (Pedra da Lua).

Another caregiver explained that, in order to reconcile housework with care, she adapted both her routine and her mother's routine:

> *Before I used to get her out of bed at half past nine in the morning, now, as I'm alone, I'm letting her sleep until a little later, so I can make lunch.* (Jade).

In addition, some interviewees mentioned that the routine of taking turns caring for other family members was suspended due to the pandemic, generating not only work overload, but also emotional discomfort:

> *Nonstop is exhausting, mentally exhausting, because she asks the same questions* [due to dementia]. (Turquesa).

In addition, caregivers combined several measures to prevent the transmission of COVID-19, which also reinforced the need to ensure the health care of care receivers while the pandemic lasts.

Ensuring health care for the elderly during the pandemic

The interviewees clarified that they were avoiding face-to-face medical care as a measure to prevent the exposure of the elderly to the coronavirus:

> *The doctor asked me to redouble my care, try to keep her* [the care receiver] *as stable as possible so she doesn't have any complications from other things, because it's not the time to go to the hospital.* (Esmeralda).

Another caregiver reported how she solved a domestic accident that happened to the care receiver during the pandemic:

> *She went to pick up an object on the floor, fell and hurt her rib.* [...] *The pulmonologist answered me on the phone, said it was not severe and that she needed to put on a bandage and use an anti-inflammatory ointment. This is being done! This happened a few days ago and now she is better.* (Ametista).

Additionally, the interviewees reported that they perform physical therapy procedures through online service, to ensure the health care of the elderly while the pandemic lasts:

> *She didn't do physical therapy for almost a month, that's why she started to feel pain* [...] *she broke her femur two years ago* [...]. *Besides the pain, she was unable to get out of bed on her own. Then I had this idea of doing virtual therapy* [telephysiotherapy] *and it is working, because the pain has disappeared and she is already getting up on her own again.* (Turquesa).

Another initiative to ensure the health care of the elderly was to guarantee that they took the flu vaccine at home:

> *I didn't have the courage to let her go to the health center so she could get the vaccine, so I paid, and the person came here at home.* (Ametista).

In addition to these initiatives, the caregivers realized that they needed to make care receivers aware of the pandemic situation.

Making the elderly aware of the pandemic

Considering that the elderly are people more vulnerable to COVID-19, caregivers, in addition to adopting preventive measures, made them aware of the pandemic. This initiative was even adopted by those who declared that the care receiver had some cognitive deficit, as exemplified in the statement by Pedra Sabão, who stopped having breakfast with her mother when she got home from work:

> *At first my mother didn't understand, but now she does. Before, she was thinking that my sisters threw me out* [laughs]. *Then I said: "no mom, it's just that there's a little germ in the air that you're from the risk group, so I can't go into your house, because my clothes are dirty". I explained it to her... it took almost 20 days, me talking every day. Now, she packs a bowl, puts in a cookie, a piece of cake, a piece of cheese and says: "So, take it to your house for coffee".* (Pedra Sabão).

The act of making the elderly aware of the emergence of COVID-19 was experienced in a peculiar way by caregivers. Those who reported taking care of dependent elderly to perform basic life activities and/or that they, according to their perception, had cognitive deficits revealed that awareness became necessary for them to understand why they were not receiving visits from relatives and friends. On the other hand, those who declared to provide care for dependent elderly people to manage their finances, leave the house alone, shop and use the phone revealed that the pandemic brought great challenges regarding the adoption of non-pharmacological measures by the elderly, as well as family conflicts:

> *A questão do meu pai que ainda anda é mais complicada, porque, por exemplo, o meu pai gostava de pegar o dinheiro dele e pagar uma conta, isso a gente não deixa mais. Só que mandar em um idoso é mais difícil do que mandar numa criança. E a questão de ser pai, nós não estamos acostumados a mandar nos nossos pais.* (Jade).

Additionally, the interviewees whose care receivers did not have cognitive deficits, according to their perception, reported another demand regarding the need to make them aware: to observe the access of the elderly to the internet and to make sure that the information they received through messages or videos on the cell phone were true. This can be seen in the following statement:

> *Now, she [elderly] has learned to use WhatsApp and receives Fake News. Then I say: "Look, this is a lie. Come here; let me show you."* (Rubi).

DISCUSSION

The results show that, although caregivers who declared to take care for elderly people with different levels of care

needs were interviewed, according to their perception, they shared several similar experiences.

This enabled the construction of the theoretical model “Caring for the elderly during the COVID-19 pandemic by family caregivers”. It was highlighted the fact that caregivers who declared to take care of elderly dependents to leave the house, manage their finances, use the phone, prepare their meal, reported that the demand for care required by them intensified during the pandemic. In addition, family conflicts arose because the elderly were resistant to adopting preventive measures. On the other hand, those who, according to the caregivers' perception, did not have cognitive deficits needed to be more actively aware regarding the pandemic.

Faced with the pandemic situation, caregivers felt uncomfortable emotions, which lead them to act in order to protect themselves and the elderly, as stated by Dr. Jerry Rawicki, a Holocaust survivor, in his interview with the renowned researcher from the North -American, Carollyn Ellis: “In my case, the concern stimulated me to prepare myself”[12].

On the other hand, in many cases, the people interviewed here stated that they felt exacerbated emotions, which needed to be mitigated in order to be able to respond to the demands that were presented. Considering the strategies punctuated by the caregivers to soften emotions, it can be inferred that they were confused and immersed in the large volume of information disseminated about the pandemic, and that, after talking to health professionals about this subject, and/or finding out about the situation, they became calmer.

In this sense, it is important to point out that the present study was conducted during the month of August 2020, and, although five months have elapsed since the beginning of the pandemic, the period coincides with the first wave of COVID-19 in Brazil[7]. This fact may justify the feelings of fear and threat that emerged from the speeches of the people interviewed, since at the time of the interviews we still did not have in-depth knowledge about the disease and we did not have the vaccine against COVID-19 as a resource available to contain the disease progression in the country. Such feelings were also reported by parents who were caring for their children with cancer during the pandemic. Some of them reported that they limited access to TV news and social networks as a strategy to face this stressful situation[13].

The infodemic phenomenon, characterized by the excess of disseminated information about COVID-19, resulted in the emergence and dissemination of information, often alarming and incorrect, which made people anxious, depressed or even exhausted and unable to react in the face of the pandemic. This phenomenon, amplified by social media, made it difficult for the population to access reliable and reputable orientation on the disease[14–16].

Therefore, in addition to fighting the coronavirus, it is also necessary to detect and respond quickly to the misinformation disseminated on social media that generates a disservice to global health[14–15,17]. An initiative developed by the International Federation of Library Associations and Institution was the creation of a step-by-step guide for the population to analyze the disseminated facts and, thus, certify whether the news is false or not[18]. However, detecting, evaluating and responding in real time to rumors and conspiracy theories represent a major challenge for public health, both in the current pandemic moment and for new epidemics and pandemic diseases[16].

Therefore, it is advisable that public policy makers and health professionals facilitate adequate communication with caregivers at the individual and collective levels. In this sense, making telehealth services feasible and encouraging the creation of structured websites that present qualified information for the population are important initiatives to improve the mental health status of caregivers of a vulnerable group such as the elderly. Such measures can also corroborate the awareness of the elderly about the pandemic. A study that addressed the impact of telemedicine on people with dementia and their caregivers identified that access to telehealth services via videoconferencing can be a useful instrument to reduce caregiver stress, as well as support them in coping with the pandemic[19].

In addition to impacting emotionally, the pandemic scenario also impacts human behavior. Thus, to protect the elderly from SARS-CoV-2, caregivers adopted several prevention measures that are consistent with the measures recommended in the literature[20]. Although these measures are important to reduce the risk of contagion, such attitudes configured work overload and emotional discomfort, especially for caregivers who had no help from others and became the only responsible for providing care to the elderly.

In this sense, the lack of informal support in the provision of care by other family members already represented, before the pandemic, a challenge in the routine of family caregivers[1,3,4], despite being documented that caregivers with social support effectively present good mental health and a low level of stress[21].

Therefore, considering the findings of a study that compared the prevalence of depressive and anxiety disorder in the adult population of the United States of America (USA), before and during the pandemic, it is assumed that caregivers could be more likely to develop disorders of anxiety and/or depression in 2020 than in 2019[5]. As no studies were

found that observed the effects of the pandemic on the mental health of caregivers of the elderly, future research addressing this topic is of supreme importance, in addition to expanding and creating support networks for caregivers who can adapt to this new reality.

At the same time, the pandemic has also compromised the guarantee of formal support for caregivers, since, to protect the elderly, they are avoiding taking them to health services, as well as receiving home care. To fill this gap in access to health, teleconsultation services were authorized in Brazil, while the health crisis caused by SARS-CoV-2 lasts, through Law No.13,989/2020[22]. Although telehealth is considered a temporary solution to cope with the pandemic scenario, studies point out that this type of care will continue after the end of the pandemic in health care services around the world and also in Brazil[23].

In short, the findings of this study show caregivers as protagonists and bring to light their needs, which are historically neglected in relation to the needs of the elderly they care for and are even more intensified in the pandemic period.

In this way, it is identified the need for health professionals to ensure that caregivers are well assisted during the pandemic, enabling care through telehealth, as well as guiding them about the pandemic, which should reflect on better care for the elderly.

In addition, at the collective level, it is essential to promote the dissemination of reputable information about the pandemic, to resolve the doubts of individuals, and thus fill the communication gaps that allow the dissemination of misinformation and end up increasing the stress of the population and caregivers of vulnerable individuals in the face of the pandemic context.

Regarding the limitations of this study, the entire sample of caregivers was composed of women, even though this research was widely disseminated on social media. Thus, it is verified that home care is still performed primarily by women, making the results of the present study a portrait of this reality and may contribute to the understanding of the phenomenon. A second limitation was asking the people interviewed what activities of daily living the care receivers were able to perform and whether they had cognitive deficits. This information may be influenced by the caregivers' subjective view, but this fact does not affect the findings of the present research, since such questioning was precisely carried out with the aim of understanding the level of care demand that the elderly required under the caregiver's perception, which is the focus of the present study.

Another limitation is that the results may indicate that some caregivers were more engaged and willing to share their experiences than those who were more severely ill. Despite this, it is important to point out that the present study respected the saturation of data through theoretical sampling, and, consequently, reflects the experiences of caregivers who reported caring for elderly people with different degrees of dependence.

CONCLUSION

The understanding of the caregivers' experience in caring for the elderly during the pandemic allowed the construction of a proposal for a theoretical model to explain this phenomenon. The emergence of uncomfortable emotions stands out as a finding of the present study when the caregivers became aware of the emergence of the coronavirus. Such emotions drove caregivers' actions to protect the elderly from contracting the virus. However, when these emotions manifested themselves in an exacerbated way, they needed to be softened so that the interviewees could adopt preventive measures. The demand from caregivers for orientation on the pandemic also emerged, as well as the need to continue the care provided to the elderly through telehealth care.

Thus, the results suggest that the emotions felt by caregivers impact their behavior and routine, even triggering an increase in the workload, in a period experienced by intense protective measures of social distancing and uncertainty in the face of the pandemic. This can compromise their health and quality of life, as well as the care provided to the elderly.

It is expected that the results of this study contribute to the preparation of health professionals and systems, with the objective of better providing comprehensive care to the elderly and their family members during the COVID-19 pandemic. Therefore, health professionals, when assisting the elderly, should also pay attention to the health of the caregiver, in addition to solving their doubts about COVID-19.

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Authorship contribution:
Conceptualization: Cristiane de Paula Rezende, Mariana Martins Gonzaga do Nascimento, Amanda Patrícia de França.
Data curation: Cristiane de Paula Rezende.
Formal analysis: Cristiane de Paula Rezende, Mariana Martins Gonzaga do Nascimento, Amanda Patrícia de França, Aline Silva de Assis Santos, Isabela Viana Oliveira, Djenane Ramalho de Oliveira.
Investigation: Cristiane de Paula Rezende, Mariana Martins Gonzaga do Nascimento, Amanda Patrícia de França, Aline Silva de Assis Santos, Isabela Viana Oliveira, Djenane Ramalho de Oliveira.
Methodology: Cristiane de Paula Rezende, Mariana Martins Gonzaga do Nascimento, Amanda Patrícia de França, Aline Silva de Assis Santos, Isabela Viana Oliveira, Djenane Ramalho de Oliveira.
Visualization: Cristiane de Paula Rezende, Mariana Martins Gonzaga do Nascimento, Amanda Patrícia de França, Aline Silva de Assis Santos, Isabela Viana Oliveira, Djenane Ramalho de Oliveira.
Writing-original draft: Cristiane de Paula Rezende, Mariana Martins Gonzaga do Nascimento, Amanda Patrícia de França, Aline Silva de Assis Santos, Isabela Viana Oliveira, Djenane Ramalho de Oliveira.
Supervision: Mariana Martins Gonzaga do Nascimento, Djenane Ramalho de Oliveira.
Validação: Mariana Martins Gonzaga do Nascimento, Djenane Ramalho de Oliveira.
Writing-review & editing: Mariana Martins Gonzaga do Nascimento, Djenane Ramalho de Oliveira.

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Corresponding author:
Nome: Cristiane de Paula Rezende
E-mail: cris7paula@gmail.com

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Maria da Graça Oliveira Crossetti

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