

EXPERIENCES OF FAMILY CAREGIVERS OF DEPENDENT OLDER ADULTS IN
THE CONTEXT OF THE COVID-19 PANDEMIC
EXPERIÊNCIAS DE CUIDADORES FAMILIARES DE IDOSOS COM DEPENDÊNCIA
NO CONTEXTO DA PANDEMIA DA COVID-19
EXPERIENCIAS DE CUIDADORES FAMILIARES DE ANCIANOS DEPENDIENTES
EN EL CONTEXTO DE LA PANDEMIA DEL COVID-19

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ABSTRACT

Objective: to understand the experiences of family caregivers of dependent older adults cared for by Primary Health Care, in the context of the COVID-19 pandemic. **Method:** research qualitative and phenomenological approach carried with 11 family caregivers of dependent elderly people in a municipality in Minas Gerais, Brazil. The interviews were recorded, transcribed and organized into categories. The analysis according to Alfred Schütz's social phenomenology and thematic literature. The interviews were recorded and transcribed to be later organized into categories and analyzed. **Results:** the categories "The care of older adult family member was intensified in the pandemic of COVID-19", "Access to formal support from Primary Health Care at the time of the pandemic", and "They hope that older adult family member will get better and not be infected by COVID-19" emerged. **Final considerations:** it is imperative that the Primary Health Care team establish an effective relationship with family caregivers of older adult so that the care offered is aligned to the real needs of both.

Descriptors: Caregivers; Aged; Coronavirus Infections; Primary Health Care; Qualitative Research.

RESUMO

Objetivo: compreender as experiências de cuidadores familiares de pessoas idosas com dependência, atendidas pela Atenção Primária à Saúde, no contexto da pandemia da COVID-19. **Método:** pesquisa de abordagem qualitativa e fenomenológica realizada com 11 cuidadores familiares de idosos dependentes de um município de Minas Gerais, Brasil. As entrevistas foram gravadas, transcritas e organizadas em categorias. A análise ocorreu segundo a fenomenologia social de Alfred Schütz e a literatura temática. **Resultados:** emergiram as categorias: "Os cuidados ao familiar idoso foram intensificados na pandemia da COVID-19", "Acesso ao apoio formal da Atenção Primária à Saúde no momento da pandemia", "Esperam que o familiar idoso melhore e não seja infectado pela COVID-19". **Considerações finais:** é imperativo que a equipe de Atenção Primária à Saúde estabeleça uma relação efetiva com os cuidadores familiares de idosos de modo que o cuidado ofertado esteja alinhado às reais necessidades de ambos.

Descritores: Cuidadores; Idoso; Infecções por Coronavírus; Atenção Primária à Saúde; Pesquisa Qualitativa.

RESUMEN

Objetivo: comprender las vivencias de cuidadores familiares de ancianos con dependencia, atendidos por la Atención Primaria de Salud, en el contexto de la pandemia del COVID-19. **Método:** investigación con enfoque cualitativo y fenomenológico realizada con 11 cuidadores familiares de ancianos

dependientes en un municipio de Minas Gerais, Brasil. Las entrevistas fueron grabadas, transcritas y organizadas en categorías. El análisis se realizó de acuerdo con la fenomenología social de Alfred Schütz y la literatura temática. **Resultados:** surgieron las siguientes categorías: “Se intensificó el cuidado del anciano familiar en la pandemia del COVID-19”, “Acceso al apoyo formal de la Atención Primaria de Salud en el momento de la pandemia”, “Esperan que el anciano familiar mejore y no sea infectado por la enfermedad del COVID-19”. **Consideraciones finales:** es imperativo que el equipo de Atención Primaria a la Salud establezca una relación efectiva con los cuidadores familiares del anciano, de modo que el cuidado ofrecido esté alineado con las necesidades reales de ambos.

Descriptores: Cuidadores; Anciano; Infecciones por Coronavirus; Atención Primaria de Salud; Investigación Cualitativa.

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INTRODUCTION

Globally, older adult population reached 202 million in 1950, increased to 1.1 billion by 2020, and is expected to reach 3.1 billion, by 2100.¹ In Brazil; older adult population was the age group that grew the most. Between 1950 and 2000, the proportion of older adults corresponded to less than 10%, similar to that of less developed countries. As of 2010, there was an increase in this proportion, approaching that found in developed countries. The percentage of this group was 15.7% in 2019, with higher rates in the Southeast and South regions of the country.²

Parallel to population aging, there is an increase in the prevalence of Chronic Non-communicable Diseases (CNCD) and these diseases can trigger dependence in older adults. Dependence can be considered as the functional inability of older adults to perform Basic Activities of Daily Living (BADL), such as feeding, dressing, and bathing, or the inability to perform Instrumental Activities of Daily Living (IADL), such as making a phone call, managing finances and communicating.³ Thus, older adults need help in performing these tasks and in managing their own lives.

With dependence established, older adults start to need care that, most of the time, is performed by people from their own families. Hence, the figure of the so-called family caregivers emerges. These family members care, many times, in an intuitive way, they perceive changes in their daily lives, such as changes in their routines, role changes, and conflicting feelings, among other aspects that permeate the care of older adult relative with dependence.⁴

In many countries, family caregivers face additional challenges in caring for older adults, such as providing care against the backdrop of the pandemic of COVID-19. In 2020, among the different age groups, the highest mortality rate from complications of COVID-19 was evidenced in older adults

(60 years or older), especially in those who had at least one of the risk factors, such as heart disease and Diabetes Mellitus.⁵

The epidemiological context raised the feeling of fear in older adults and in the family caregivers for the fact of a possible hospitalization of their loved ones, without the right to the presence of a companion, making them think about this solitary hospitalization and the risk of losing their relative.⁶ Negative feelings experienced by family caregivers can often be reported due to the abdication of one's own needs in order to care for the other.⁶ However, it is observed that the context of the pandemic of COVID-19 seems to intensify and trigger other adversities that interfere in the daily life of this social actor.

Thus, it is essential that the health team works in Primary Health Care (PHC), which is the first point of care and the preferred entrance door to the Brazilian National Health System and knows the experiences of these family caregivers of dependent older adults in the context of the COVID-19 pandemic, to support them, meeting their needs, under the prism of integrality.

It is important to point out the scarcity of productions that address the experiences of the family caregiver of dependent older adults in the context of the pandemic of COVID-19, especially because the pandemic is a recent phenomenon. Sharing these experiences may contribute to the design of comprehensive and longitudinal care by the health team that operates in PHC, including Nursing, in addition to raising reflections that may culminate in the establishment of health practices.

OBJETCTIVE

To understand the experiences of family caregivers of dependent older adults cared for by Primary Health Care, in the context of the COVID-19 pandemic.

METHOD

Qualitative research with the theoretical and methodological framework of Alfred Schütz's social phenomenology.⁷ Social phenomenology considers the meaning of individuals' actions in the social world. Action can be considered conscious and intentional conduct. To understand the actions arising from past and present experiences, we look for the "reasons why" and to know the expectations, the reasons in view of which one wants to act, that is, the intentionality, we look for the "reasons for".⁷ In this study, the set of "reasons why" and "reasons for" of the experience of family caregivers of older adults with dependency in the context of the COVID-19 pandemic is presented.

It is noteworthy that the research met the steps recommended by the Consolidated Criteria for Reporting Qualitative Research (Coreq).⁸ In the selection of the intentional non-probabilistic sample, the family caregivers of older adults with some type of dependence of both genders were included; responsible for their partial or full daily care for a minimum period of three months, in the home context. The family caregivers who were in a period of home isolation due to COVID-19 were excluded.

It is worth mentioning that, in order to integrate the sample, the family caregivers answered if they helped older adults in some of the BADLs and/or IADLs. No instruments were used to measure older adult's dependence.

Researchers were granted access to participants after the Research with Human Beings Ethics Committee of Governador Ozanam Coelho University Center, CAEE: 42901821.4.0000.8108, issued Opinion no. 4.545.273, on 02/18/2021, approved the study.

The study was developed in the municipality of Piraúba, located in the Zona da Mata region of Minas Gerais, which has four Primary Health Care Units (PHCU) and 100% coverage of the Family Health Strategy. The estimated population is 10,866 inhabitants, 15.3% of whom are 60 or older.

Thus, the nurses of the four PHCUs were contacted, and they authorized the contact with the community health agents, who provided the names and telephone numbers of the potential participants. Next, family caregivers were contacted by telephone to be introduced and certified as to the inclusion criteria of the study. The degree of older adult's dependence was not measured; it was enough for the family member to report it to meet the inclusion criteria. Subsequently, a visit to the home was made to explain the research objective and invite the family member to participate in the study. After the initial acceptance, the date and time for the interview were scheduled.

Data was collected by two Nursing students (scientific initiation scholarship students) using the phenomenological interview technique, which allows face-to-face contact between the interviewee and the researcher, enabling the capture of the phenomenon experienced from the exchange and interaction between these two social actors.⁹ Data collection occurred in the first semester of 2021, outside the caregivers' homes (in the backyard or on the porch), respecting the biosafety procedures recommended to prevent the transmission of COVID-19. These procedures included: the use of a surgical face mask, alcohol gel, and a physical distance of at least one meter from the participant.

Before starting the interview, the ethical aspects involved and the need to sign the Free and Informed Consent Form were clarified to the participant. The interviewees' permission to use an audio recorder was requested in order to allow the recording, in full, of their statements, as well as their subsequent analysis. The data collection environment provided privacy, had little noise, was free of interruptions, and allowed good air circulation. The average duration of each interview was 30 minutes. To facilitate the conduct of the interview, the authors prepared a semi-structured script with the following questions: How is it caring for your older adult relative at this time of the COVID-19 pandemic? What do you expect when you take care of your older adult relative? In addition to these questions, personal and socioeconomic data were added to the data collection script.

Eleven interviews were conducted, and all the statements obtained were included in the study. It is worth mentioning that there was no refusal or withdrawal to participate in the research. The number of participants was not established a priori. The data collection ended when the significant content of the statements was obtained and no new themes emerged, indicating that the research objective was reached and the questions that guided the research were answered.¹⁰

The audio recordings were stored in a place where only the responsible researcher could access them. To ensure anonymity, the statements were identified by the letter "I" (interview) followed by Arabic numerals corresponding to the order of the interviews. The organization and analysis of the results were based on assumptions described in a theoretical study based on Alfred Schütz's social phenomenology.¹¹

First, the transcription of each statement was made. Then, they were read and reread in a detailed manner, distancing themselves from the theory, to enhance the meanings explained by the interviewees. After that, we proceeded with the comprehensive analysis and the organization of the statements, whose content was grouped by similarity of meanings, providing the opportunity to build thematic categories. The past and present experiences of the family caregivers of dependent older adults in the context of the pandemic of COVID-19 resulted in the construction of categories referring to the "reasons why", while the expectations tangible to this care of older adult relative converged to the formation of the category that expresses the "reasons to".

The "why" of human experience can be understood as irrevocable and irremediable because it has been or is being realized.¹¹ Therefore, by turning to the past, the family caregiver has the opportunity

to become an observer of their own acts and apprehend the motives that led them to perform certain actions in the life world, which is the everyday world. In contrast, when the family caregiver turns their intentionality toward the other and attributes a set of motives in view of which they want to act (expectations), what Schütz called "motives for" is revealed.

Finally, the results obtained were interpreted based on social phenomenology and the theoretical framework related to the studied theme.

RESULTS

The studied group was characterized, mainly, by family caregivers predominantly female (90.9%), who lived with at least one person, with a variety of ages between 38 and 62 years, married, with a low level of education, being most evident the incomplete Elementary School. The family members had been exclusively dedicated to the care of older adult relative for approximately nine years, varying from four to 14 years.

The care of older adult family member was intensified in the pandemic of COVID-19 (reasons why)

Care for older adult family member was intensified in the pandemic of COVID-19, culminating in the perception of burden and that this care is exhausting. Caregivers also gave up personal matters to be more available to their older adult family members.

I always took care of her, but at this time of the pandemic, I take more care of her [...] I gave up many things, I can't leave the house... if I need to go to the bank or go out, my sister takes care of her for me, but I don't take long to come back. (I1)

I have always taken great care of her, mainly because she is a bedridden person, but with the pandemic, the care is being redoubled. (I2)

I don't have time for myself, my time is all for her, to take care of her; during the pandemic, the care is greater. I'm the only one who takes care of her, so it's very tiring because I have a house, a husband, and a daughter. It was a big overload; I stopped walking and taking care of my health. (I3)

I have not experienced any despair regarding COVID; I have been following all the protocols and caring more than before. I have been called ignorant and antisocial at times. (I8)

Operationally, the precautions to prevent COVID-19 were to wear a mask, use alcohol gel, avoid using public transportation such as the bus, avoid walking on public roads and restrict home visits.

We use a mask, we use alcohol [...]. I don't use the bus anymore. (I1)

Before, we used to walk in the street up to a certain point. Now, we don't go anymore, because I avoid leaving the house with her.... We take a walk in the garage [...] I don't let her shake anyone's hand [...] we wash our hands and pass alcohol. (I5)

I don't let my mother get close to my grandchildren. [...] until today, I am like that, I don't let anyone come without a mask. (I7)

I really don't allow people in the house to visit, I have kept the whole isolation scheme for personal reasons and also to maintain their physical integrity and health. (I8)

When we go out to the doctor's appointment, we wear a mask and carry alcohol gel... I get a little scared [...]. (I9)

Access to formal Primary Health Care support at the time of the pandemic (reasons why)

The family caregivers mentioned that they count on the support of PHC professionals, such as physicians, nurses, and community health workers. The team's actions mentioned by the caregivers were: consultations, vaccination, home visits, and scheduling exams.

I have assistance from the health center; they came to the house to vaccinate her against COVID. (I2)

I get help from the health center when I need it. The doctors and nurses are at home. They vaccinated us for the Coronavirus. (I3)

I get help from the health center for flu shots and COVID, and when we need it, the doctor or nurse comes to the house for a consultation. (I4)

My mother is well assisted; when we need a doctor, we call and they come to her house... The health agent gives us good assistance. We make an appointment and they come. [...] We took them to the clinic for vaccinations, but they gave us vaccinations in the car, it was very quick. (I6)

They hope that older adults relative will get better and not be infected by COVID-19 (reasons for)

The intentionality of family caregivers is that older adults get better and not be infected by COVID-19, as infection could worsen or aggravate the clinical picture.

I hope the pandemic ends, that she doesn't get COVID [...] I really hope she gets better. (I2)

I hope it will get better and better and better [...] that it doesn't have COVID. (I3)

I hope she gets better and doesn't get sicker. She already has health problems, and if she has COVID, it will be worse. (I4)

I hope she will be fine. I am sad when she says she is not very well, but I keep hoping she will get better. During the pandemic, I intend for her to feel well, not to get the disease (COVID-19). (I6)

I hope they get better [...] I want, for him, is to do my best, to see them well, healthy even more, in this phase when they pass ninety where there are these limitations. I hope they don't catch the virus (COVID-19). (I8)

I hope the pandemic ends...that she can get better. She has already had the vaccine, but I am not careless [...] I take care of her with great care. (I9)

I hope she doesn't get the "corona" [...] I wish her to get better. (I10)

I hope she feels good about what we are doing for her, I feel reassured to be with her. I don't want her to get COVID. (I11)

DISCUSSION

It was identified that most of the group interviewed was composed of married women with age variations between 38 and 62 years. An integrative review study pointed out that, frequently, family caregivers are female, wives or daughters, aged 50 years or more.¹² They assume a multiplicity of social roles: related to caring for older adults and those that were already part of their daily lives (being a mother, wife, responsible for preparing meals, taking care of household activities, among others). Regarding the level of education, it could be noticed that other studies involving family caregivers of older adults also pointed out the low level of education.¹³⁻¹⁶

The results of this study show that the experiences of family caregivers of dependent older adults in the context of the pandemic of COVID-19 congregate past and present situations (reasons why), characterized by intensified care, with the use of mask, alcohol gel, avoiding the use of public transport such as buses, also avoiding walking on public roads and restricting home visits, as well as they claim to have access to formal support from PHC at the time of the pandemic.

The care provided by family members was already recognized as a contributing factor to the feeling of burden before the pandemic, due to the multiple care tasks performed, such as: providing food, hygiene, administering medications; keeping them company; accompanying them to medical appointments or to various tests.¹³ When analyzing that this care is robust from the perspective of the family caregivers themselves and that, with the pandemic of COVID-19, it has been intensified, one can infer that the chances of overburdening have increased.

The feeling of being overloaded can trigger illness resulting, mainly, from uninterrupted work, which corroborates social isolation and low financial conditions, since caring does not allow, in general, other paid activities.¹⁶ Illness is more related to mental health and musculoskeletal disorders.¹⁶

Therefore, caregiving will always affect caregivers. They may have worse physical health compared to the general population, more frequent use of medications, high prevalence of depression and anxiety, stress, and lower life satisfaction, as well as higher financial expenses related to higher electricity bills, medication costs, and geriatric supplies, and home adaptations.¹⁷

The restriction of home visits is configured as a recommended measure for protection against COVID-19, among the other protective measures. However, this social withdrawal can trigger, in the caregiver, the perception of higher levels of depression, anxiety, and stress, especially in women.¹⁸ Although not mentioned in this investigation, these negative feelings may contribute to the caregiver's increased consumption of alcoholic beverages.¹⁹

A study in Chile also found that family caregivers of older adults made extensive use of care supplies such as alcohol gel, soap, and masks.²⁰ Additionally, it is recommended that people keep their distance; avoid hugs and kisses; sanitize glasses, cell phones, and personal objects; clean shoes with a cloth soaked in 70% alcohol or sanitary water (hypochlorite); separate the clothes used to leave the house in their own plastic bag, separate from the living area of older adults; keep the environment ventilated; sanitize your hands, as well as surfaces of frequent contact, such as handrails, doorknobs, chairs, switches, remote controls, handles and others and, in case of coughing or sneezing, maintain respiratory etiquette, that is, cover your mouth with your elbow and then sanitize it.²¹

These aforementioned guidelines should be widely disseminated by the PHC team, which is a device for coping with COVID-19. In this sense, the participants affirmed that they count on the formal support of the PHC at the moment of the pandemic. However, the family caregiver, even living with older adults and being registered in the PHC unit, is not approached because of their own demands, but as an informant of the health conditions of the dependent older adults.¹⁶ The importance of taking care of the cared for is reinforced.

The experiences of family caregivers of older adults with addiction in the context of the COVID-19 pandemic showed that care was intensified. This robust care may contribute to negative health outcomes; however, this group relies on the support of the PHC team in their aftercare. It is emphasized that it is imperative that the PHC team establish an effective relationship with these family caregivers so that there is reciprocity of intentionality¹¹, that is, the care offered is aligned to the real needs of this public.

PHC configures itself as an opportune scenario for the realization of practices aimed at encouraging self-care and greater satisfaction with the role of caregiver, strengthening beliefs, performing

physical activities, and adherence to community programs focused on psychoeducation and emotional assistance.²²

A home visit is an important tool for the attention to the family caregiver because, besides facilitating access to the service, it represents a privileged space for the construction of the bond, of the intersubjective relationship. From the establishment of this relationship permeated by reciprocity, the health professional gets tools to get to know the living conditions and habits that help him/her to identify health needs.

The statements also revealed expectations (reasons for) that older adults relative will get better and not be infected by COVID-19. It is expected that the participants express feelings of hope about the future, as evidenced in the statement "I hope he gets better". This is because there is an affective bond between the caregiver and older adults, and the feeling of hope seems to strengthen and encourage them to face adversities, especially in a scenario of uncertainty caused by the pandemic.

Although this study approaches important aspects of the experiences and expectations of family caregivers of older adults in the context of the pandemic of COVID-19, it presents some limitations. Thus, as it is a qualitative study, the results presented constitute specific evidence of the group studied, which belongs to a certain reality that can be different from another, which prevents the generalization of the results. Therefore, other investigative possibilities need to be considered and implemented.

As implications for Nursing practice, this study points out the need to pay attention to the family caregivers of older adults, who perform care in a more intensified manner in the context of the pandemic of COVID-19. In this sense, nursing, which commonly takes a leadership role in PHC, may reflect and develop actions, together with the team, that aim at the completeness of care to this public that, sometimes, is recognized only as an informant of the health conditions of the dependent older adults.

FINAL CONSIDERATIONS

The experiences of family caregivers of dependent older adults in the context of the pandemic of COVID-19 were permeated by intensified care due to the epidemiological picture. Participants mentioned the perception of overload and that this care is exhausting. Operationally, the precautions to prevent COVID-19 were: the use of masks; alcohol gel; avoiding using public transport such as buses; avoiding walking on public roads, and restricting home visits.

Family caregivers reported having the support of PHC professionals, such as physicians, nurses, and community health agents. The actions received by the team were: consultations, vaccination, home visits, and scheduling exams. The expectations of the sample studied refer to the improvement of the epidemiological scenario and to the non-infection by COVID-19.

It is noteworthy that, although caregivers have access to PHC, the assistance performed is strongly focused on older adults. Given this result, we recommend actions of continuing education for PHC teams, equipping them to develop care plans that consider the singularities of each caregiver. It is also recommended the increase home care due to the possibility of subsidizing the bond, the exchange of knowledge between the different social actors involved, and contribute to comprehensive care.

CONTRIBUTIONS

All authors contributed equally to the design of the article, data collection, analysis and discussion, as well as writing and critical revision of the content, with intellectual contribution, and approval of the final version of the study.

CONFLICTS OF INTEREST

None.

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