Perceptions of elderly people who care for other elderly people in times of the COVID-19 pandemic

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Abstract

Objective: To identify the perception of older adults who are caregivers for other older adults about the care offered, as well as the strategies for coping with difficulties in this process from the perspective of *Coping Theory* in the context of COVID-19. *Method*: This is a henomenological study, with elderly people and participants in the Universidade Aberta à Maturidade, Program of the State University of Paraíba. Data collection instruments were a sociodemographic questionnaire, and semi-structured script. Interviews were carried out via video call and the data was evaluated by Content Analysis. *Results*: 17 elderly caregivers aged between 60 and 79 years participated. Three thematic categories were listed: 1) Difficulties faced during the pandemic period; 2) Coping strategies used during the pandemic; 3) Needs for improvement in the performance of the caregiver role. *Conclusion*: we found evidence of increased stress, presence of anxiety and risk of overload. In these circumstances, the participants developed coping strategies through education, use of social networks and seeking support.

Keywords: Psychological Phenomena. Aging. Adaptation Psychological. COVID-19. Caregivers.

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INTRODUCTION

The significant increase in the older adult population in Brazil has facilitated discussions in public agendas aimed at promoting healthy aging through the National Policy for Older Adults and care guidelines. However, there is still much progress to be made in terms of preserving the autonomy and independence of older adults[1]. Especially when, in the aging process, there is a need for family support or someone to assist the older adult in Activities of Daily Living (ADLs). In this scenario, the figure of the caregiver emerges, a fundamental component in the home care of a dependent older adult.

The caregiver also becomes a focus of attention, considering that providing direct care to an older adult can cause mental and physical distress. In this regard, since the responsibility primarily falls on family members, it is worth noting that, in most cases, they do not have the adequate training to perform the various activities related to the role of caregivers for their older adults[2].

Given this context, the possibility of overload and stress becomes a reality for the caregiver, especially when the person assuming the caregiving role is also experiencing the aging process, which makes the situation even more detrimental. Supporting this perspective, studies observe that in the context of home care, there is a high rate of older adults caring for others who are more dependent. An older adult assuming the care of another older adult can predispose to an even greater condition of overload for the caregiver, as individual needs and the accumulation of caregiving tasks can interact and generate greater distress[3,4].

Considering the possibility of stressful events related to the execution of ADLs and the lack of training to deal with the work, this reality experienced by a caregiver who is going through their own aging process brings with it a new configuration that is further complicated by factors such as fatigue, lack of motivation, sadness, etc., interacting with each other[2,5].

Furthermore, it is necessary to emphasize that the significant period of coping with the COVID-19 pandemic posed an even greater challenge for older adults who care for other older adults during this time. The novel coronavirus (SARS-CoV-2), an acute respiratory disease, became a global public health issue, and a state of pandemic was declared in March 2020. The older adult population has shown greater vulnerability to the more severe forms of the virus and a higher risk of death[6].

Studies demonstrate that caregiver burden increased during the COVID-19 pandemic, and this escalation in the intensity of responsibilities may have led to a higher risk of health problems, including chronic diseases. Reports of elevated levels of stress and burden have become alarming, highlighting that the demands placed on these caregivers were neglected. Social isolation weakened access to support networks, and difficulties in accessing technologies pointed to the need for discussions regarding support for family caregivers, particularly older adults caring for another older adult[7-9].

In line with the context outlined, this work is grounded in the Coping Theory, developed by Folkman and Lazarus, considering it as an important resource to enable the creation of new strategies in the face of situations deemed detrimental to the well-being of the older adult caregiver[10]. It is understood that faced with stressful events and the possibility of overload resulting from the caregiving role, coupled with issues inherent to the personal aging process and the context of social isolation due to the COVID-19 pandemic, it was necessary to assess how older caregivers cared for other older individuals and reflect on how they developed strategies to prevent more intense psychological suffering during the pandemic.

The aim of this study was to identify the perception of older adults who care for other older adults during the COVID-19 pandemic, from the perspective of Folkman and Lazarus' Coping Theory[10].

METHOD

This is a descriptive, exploratory study of a qualitative nature with a phenomenological approach, aiming to understand how individuals experience certain periods. It was conducted with older adult participants of the Universidade Aberta à Maturidade (UAMA - Open University for Maturity) Program, from a public university located in the municipality of Campina Grande (PB), Brazil.

The UAMA Program began in 2009 and has since served an average of 100 registered students, with an age range typically spanning from 60 to 91 years old. The program offers courses with a workload of 1,400 hours over four semesters.

The sample was obtained by convenience, and the study's sample universe comprised all older adult participants in the UAMA programs in Campina Grande (PB), among whom those who met the inclusion criteria for the research were identified. The inclusion criteria were: being aged 60 years or older and self-perceiving as a caregiver for another older adult during the pandemic. The exclusion criteria were: inability to participate fully in the interview due to technical issues, such as unstable internet connection throughout the interview.

The steps followed for recruitment were as follows: 1) Initial contact with the UAMA Program coordination, requesting the presentation of the invitation to participants for participation in the research; 2) Identification of participants who met the inclusion criteria and wished to participate; 3) Selection of participants according to the previously established criteria, contacting them and scheduling interview times.

Virtual interviews were conducted via video call, following contact with the researcher, a health psychology master's candidate, during which the study's objectives were presented. The video call would take place in an environment that ensured privacy and could involve the presence of another person to assist the older adult, if necessary, in using technological resources. Data collection took place between May and June of the year 2022.

For data collection, the following instruments were used:

1) Sociodemographic questionnaire aimed at characterizing the sample regarding: age, education level, occupation, socioeconomic status, presence of any physical or mental illness, family arrangement, and activities performed in the caregiver role.

2) Semi-structured Interview Guide comprised of the following questions: What does it mean to you to be a caregiver for an older adult? How do you feel about taking care of another older adult? What is your daily routine like? How do you feel about your daily caregiving routine? What changed with the COVID-19 pandemic? What are your greatest challenges in caring for another older adult during the COVID-19 pandemic? What coping strategies do you employ during the COVID-19 pandemic? How do you take care of yourself during the COVID-19 pandemic? How?

The analysis of the interviews was conducted using the Content Analysis Technique systematized by Bardin[11] and the Coping Theory, considering coping strategies for caring for older adults based on problem-focused and emotion-focused approaches. The interviews were recorded and transcribed by a researcher. After data review and confirmation, they were meticulously selected through analysis considering the aspects proposed in this study. The responses to the open-ended questions were subjected to thematic categorization. The subsequent steps included the pre-analysis process, data coding, and finally, categorization and quantification of the record units.

Throughout the development and execution of this work, ethical care was ensured in terms of guidance, confidentiality, and secrecy, guaranteeing the voluntary and informed participation of the subjects in accordance with the guidelines outlined in Resolution number 466/12 and 510/16 of the National Health Council and the Ministry of Health. Technical guidelines for online interview research were also followed. Additionally, participants were provided with precise clarification regarding the voluntary nature of their participation, with the assurance that they could refuse to participate or withdraw their consent at any point in the research without any consequences. This study was approved under approval protocol number: 5,142,895.

DATA AVAILABILITY

All data supporting the findings of this study are available upon request to the corresponding author, Gilclean Delfino Leite, as they contain information that compromises the privacy of the research participants.

RESULTS AND DISCUSSION

Out of 20 older adults invited, 17 participated in the study, comprising the final sample, with three participants lost due to inability to maintain connection throughout the entire online interview process due to technical issues. Thus, out of the 17 participants considered caregivers of other older individuals, 13 (76.47%) were female, and four (23.52%) were male. Ages ranged from 60 to 79 years, with seven participants (41.17%) in the age group of 60 to 69 years and ten (58.82%) in the age group of 70 to 79 years. Regarding family income, the majority reported receiving more than three salaries, with a percentage of 64.7% (n=11), between two and three salaries were reported by 23.52% (n=4), and only two participants stated receiving between 1 and 2 salaries, with a percentage of 11.76%. Regarding the degree of kinship of those residing with the caregiver older adult, the most predominant were: spouse with 58.82% (n=10), children with 41.17% (n=7), those living with parents, and those living with siblings had the same percentage of 11.76% each. It is important to note that in this last category, it is necessary to consider the possibility of two or more relatives living with the caregiver older adult.

When asked about their self-perception of health, the participants reported the following issues: hypertension (76.47%, n=13); diabetes (35.29%, n=6); some type of bone disease such as osteoporosis, osteoarthritis, or arthritis (35.29%, n=6). When questioned about psychological issues, 35.29% (n=6) reported having experienced anxiety, and 17.64% (n=3) reported having had depressive behavior.

The sociodemographic profile revealed that the majority were female caregivers with low incomes, who were alone with the dependent older adult during the pandemic due to social distancing rules. It also demonstrated, with the peculiarities of each context, the limited support for the caregiving older adult, as a large part lives alone with their dependent older adult; the presence of one or more physical and/or emotional health issues; and caregiving provided for a period of one year or more.

Considering the routine of caregiving, it was possible to list the main caregiving activities that participants mentioned as part of their daily tasks: being present with the individual—ensuring they are not alone or feeling lonely; financial management, providing food, clothing, hygiene, sleep and rest, leisure and entertainment, health care, and medication management.

It was noted that the activities mentioned pertain to Activities of Daily Living (ADLs), indicating that some of the older adults being cared for had a higher degree of dependency. Thus, through the semi-structured interviews, participants were able to share their perceptions and experiences as caregivers during the pandemic period and whether it was possible to develop coping strategies to handle the most stressful situations.

Chart 1 presents the thematic categories perceived by older adult caregivers caring for older individuals during the COVID-19 pandemic.

Chart 1. Presentation of the thematic categories perceived by older adult caregivers caring for older individuals during the COVID-19 pandemic. Paraíba, Brazil, 2022.

Category I – Perception of difficulties of older adult caregivers
• Subcategory A – Perceptions of existing routine difficulties; • Subcategory B – Perceptions of intensified difficulties during COVID-19, related to social isolation; • Subcategory C – Perceptions of difficulties with their own health.
Category II – Developed Coping Strategies
• Subcategory D - Problem-Focused Coping – Expressions of coping based on active actions aimed at altering the harmful situation; • Subcategory E - Emotion-Focused Coping – Expressions of coping with actions to alter the individual's emotional state, seeking to reduce the unpleasant feeling of the stressful situation.
Category III – Perception of Improvement Needs

Category I: Perception of difficulties of older adult caregivers

Subcategory A - Perceptions of existing routine difficulties:

When questioned, all participants reported feelings related to the difficulties in their caregiving routine, which were considered potential stressors due to their repetitive nature, intensity, and the health condition of the caregiver themselves:

> "I've been taking care of her for 38 years. She's my sister, but she's very impulsive, gives me a lot of trouble, rebellious person. You have to have a lot of patience and a lot of composure to face, to help. And mind you, it's every single day of the year, there's no break." (P.4)

As a result of the quantity of responsibilities, the specificities of caring for the dependent older adult, and the aging process itself, the caregiver experiences psychological distress due to the inability to effectively deal with such issues. This was marked by the statement:

> "You need a lot of patience, you need to have a lot of nerves at this moment, this reality worries me a lot, but you need to help. When it comes to food, you have to be very careful, very nervous. [...] It really affects me because I'm already nervous, you know? So, everything worries me and makes me anxious." (P.16)

It is possible to observe a lack of training and support for the older adult caregiver who, in certain situations, may not recognize ways to cope with the inherent demands of this stage of life, resulting in a circumstance with a higher likelihood of stress and overload[5,12,13].

Subcategory B - Perceptions of intensified difficulties during COVID-19, related to social isolation.

In this category, participants were questioned about the period of the COVID-19 pandemic and what perceptions they had regarding caregiving and the changes that brought them the most impact:

> "They were distressed about going out, but I wasn't because it was something I needed, it was a necessity. I had to go to the supermarket, I had to go to the pharmacy, I had to take my mother to the doctor. The isolation was very difficult, very distressing. We isolate ourselves, had fear, keep thinking who would be the next tomorrow. It could be a family member, but always with that hope and praying to God that it wouldn't happen." (P.8)

The need for mobility during the pandemic has been identified as a risk factor, as it exposes older adult caregivers to potential infection when they must leave their homes to perform caregiving tasks. In this scenario, there is also a perception of reduced social support and lack of assistance[13,14].

Those who assumed the care of older adults with dementia-related disorders faced an even more challenging circumstance[9].

> "During this pandemic time, we were more confined, right? We were like: 'Oh my God!'. Even the children, we think: My God, why don't my children kiss me anymore? Why don't my children hold my hand anymore? In reality, these things became more difficult because of her problem, it's already not easy, and it became even harder because of her problem." (P.14)

There was a decrease in social contact with family and the community, reducing the possibility of support in activities related to the caregiving role and corroborating feelings of emotional and physical exhaustion [8,15-17].

Subcategory C - Perceptions of difficulties with their own health

When questioning participants about their self-perception of health, issues related to physical pathologies as well as increased mental distress were mentioned:

> "Look, I have hypertension, I had a CVA (cerebrovascular accident), I'm pre-diabetic, I also take medication for anxiety. I had to stay calm because there was no other way, I couldn't let stress take over everything. I had to accept it, it increased the anxiety, but everyone had that." (P.10)

Studies have shown that stress, depressive behaviors, and anxiety were some of the leading causes of greater psychological distress among older adult caregivers, reaching high levels in some cases during the COVID-19 pandemic[18-21].

> "I find it very heavy, very heavy. Because there are times when I feel exhausted. Exhausted like 'Lord, help me, my God!'. But it's difficult, very, very difficult. Draining is the word. And I was in this prison at home, I don't know how, but I escaped." (P.6)

According to Coping theory, individuals may assess the adverse situation and develop coping strategies as a physical or mental response to manage this process beneficially. These strategies can be learned, employed, or disregarded[18-20].

Category II: Developed Coping Strategies

Subcategory D - Problem-Focused Coping - Expressions of coping based on active actions aimed at altering the harmful situation.

In this aspect, adaptation and change strategies are considered, as the individual understands what is happening and tries to act in a way that makes their goal of removing or reducing the impact of the experienced situation effective. The objective is to deal with the threat, harm, or challenge in a way that the individual can perceive the alteration of the stressful event[18-21-22].

> "But I went anyway, I just didn't hug and tried to explain the distancing. I took care of myself, did everything they advised, wore a mask, used hand sanitizer, kept my distance from people, and stayed in touch virtually, that helped. I take my medications on time, try to sleep well, and I also try to take care of my diet, so I consider that I do take care of myself." (P.17)

> "And the virtual classes, it improved a lot, I reunited with friends, we thought we were living. I never lost contact. Now it was a fearful contact, I felt obliged to keep my distance, afraid of acquiring or transmitting. A terror, as if I were the carrier, the one to blame for that or for having brought it." (P.6)

Considering the perspective one has of the stressful event, the individual can assess what can be put into practice to confront what jeopardizes their well-being. Seeking guidance and social support provides a strengthening of bonds and enables the creation of new coping strategies[14-23].

Subcategory E - Emotion-Focused Coping - Expressions of coping with actions aimed at altering the individual's emotional state, seeking to reduce the unpleasant sensation of the stressful situation.

> “I have had a hobby since my childhood, I really like reading, reading has always been an escape for me. When I have a problem, for me, I open a book and forget, I forget, you know? But you try to make friends, like I was eager, looking for someone to talk to, because I didn't have the opportunity with my husband's illness, I sought friendships.” (P.2)

> “Knitting, mandala, crochet. Each mandala, the most beautiful things in the world. [...] I just stayed at home and communicated a lot through the internet, right? with the guys. But it was really bad, very stressful. I panicked, there were times when I said, 'My God, will I escape?' I prayed for everything I had and didn't have the right to in this life. I'll just laugh, because if you take it seriously, you get sick.” (P.6)

Emotion-focused coping strategies aim to distance oneself or escape from the problem for emotional stabilization in response to what has been affected by the stressful circumstance. The individual withdraws from confronting the stressful event[10,24].

In this situation, there is a regulation of the emotional response caused by the stressful situation, which may even involve denying or avoiding dealing with it realistically. It is observed that hobbies, humor, reading, and manual work are examples of emotion-focused coping strategies, involving a non-direct defensive process towards the problem. Participants also reported issues related to spirituality, aiming for care, protection, and motivation to continue performing their role.

> “My therapy during the pandemic was keeping my mind occupied, working, doing household chores, I didn't stop. I participated in the rosary on television, the mass. I like to communicate via WhatsApp with my friends, talk to people, and that was it.” (P.8)

> “In the afternoons, I do crafts, semi-jewelry, then it's time to make dinner, after dinner on Tuesdays and Thursdays, I watch the online worship service. Being in church, even if it's online, helps a lot. I spent the whole day with my music, my praises, I put it on YouTube, listened to messages from other pastors that made me feel good. And making my jewelry.” (P.9)

There are also emotion-focused coping strategies that can be detrimental to the individual's health, serving as avoidance of the stressful situation through the use of substances such as alcohol, cigarettes, or medication. In this situation, the possibility of abuse may even be intensified[20-25].

> “There are times when I even get angry, which is normal because it's not possible. We... get stressed from insisting. There are times when I need an outing, like today, at the UAMA. It renews me, I mess around, I just go for that, I really like to play, to blow off steam. Then I come back feeling very re-energized, you know?” (P.6)

Category III: Perception of improvement needs

When observing and evaluating the stressful event, the individual can identify opportunities for action and what needs to improve in order to cope with outcomes that bring about a reduction in the damages or risks experienced. Reports of difficulties regarding the healthcare system and the need for education were noted.

> “But when she arrived at the hospital, according to what my daughter reported, it seemed like... the People's Park. She got in because she was on the SAMU (Mobile Emergency Care Service) stretcher, but they put her in a bed and she spent 16 hours without assistance because there were so many people... And the number of doctors and nurses was very low. [...] She came home still with the same symptoms.” (P.2)

> “We never stop learning, I have been learning many new things. I started to realize that after the children left home I was entitled to a life, new friends, new activities, new everything, you know? So it was very gratifying. The pandemic brought about distance from people, but other than that, we are getting through it.” (P.3)

In a study on informal home caregivers, the importance of reflecting on how the well-being of caregivers is widely neglected in research literature was discussed. Additionally, the study asserts that policymakers overlook the lack of healthcare training among caregivers, lack of knowledge about illnesses, psychological issues, general medical care, economic difficulties, and many of them do not reside in housing adapted to existing needs or face difficulties accessing healthcare services[26].

> “In reality, my house, back when we were poor, didn't have the conditions to fix it up in a suitable way and the house has a lot of thresholds. And these thresholds are not suitable for an older person, especially her, who has already broken her femur. [...] One new thing I learned recently that I had never really used before was the phone. The phone has helped a lot." (P.14)

It was found that the lack of technological education hindered access to information about caregiving and even the possibility of receiving assistance through digital channels. Due to this limitation in access and contact, even situations of violence may not have received the proper attention and care[8,27-29].

This study has some limitations. Among them is the impossibility, within the data collection period, of reaching a larger number of older adult caregivers or examining other caregiving conditions related to the community, as well as not utilizing the data saturation technique, which could lead to a biased perception. Thus, the sample consisted only of participants from the UAMA Program, who had communication opportunities via online platforms, through digital inclusion and the program's socialization process. In line with this purpose, the urgent need for further studies dedicated to the topic becomes notable.

CONCLUSION

Older adults who cared for other older adults, according to their self-perception of home caregiving during the COVID-19 pandemic, faced difficulties such as apprehension, distress, lack of care for their own health, and lack of training and information to care for aging during a pandemic.

It was also possible to identify coping strategies used during the pandemic, such as adaptation, resilience, manual work, reading, use of technological environments, and participation in online groups like the UAMA Program, which provided emotional support. Additionally, practices related to religiosity were noted, alongside identified needs for improvement in caregiving execution. There was evidence of increased stress, presence of anxiety, and risk of overload. In these circumstances, individuals developed coping strategies through education, use of social networks, and seeking support.

This study demonstrates its relevance by highlighting a gap in knowledge and scarcity of scientific literature on older adult caregivers who cared for other older individuals during the COVID-19 pandemic. In this period of social isolation, there was significant distress regarding the mental and physical suffering of family caregivers who were alone with their elderly ones at home.

It is concluded that there are viable strategies for improving the conditions of older adults who care for other older individuals. It is noteworthy that the information received is crucial for establishing numerous possibilities for action and improvements in the lives of this population, as well as interventions and support. It is proposed, therefore, to promote knowledge and training aimed at reaching this population and ensuring their protection, care, and rights.

AUTHORSHIP

- Gilclean Delfino Leite - Formal analysis, conceptualization, writing curation - initial drafting, writing, data analysis and interpretation - editing review.
- Fabiola Araújo Leite Medeiros - Guidance, formal analysis, conceptualization, writing curation - critical review, approval of the version to be published.

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