

Quality of life of informal caregivers of aged people with alzheimer's disease during the COVID-19 pandemic

Qualidade de vida do cuidador informal de idosos com doença de alzheimer na pandemia COVID-19
Calidad de vida de cuidadores informales de ancianos que padecen mal de alzheimer durante la pandemia de COVID-19

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Abstract

Objective: To reveal the quality of life of informal caregivers of aged people with Alzheimer's disease in times of the COVID-19 pandemic. **Method:** A descriptive and qualitative study conducted through semi-structured interviews with 12 informal caregivers of older adults, selected by convenience. Data processing was performed using the IraMuTeQ software and class analysis using the Strauss and Corbin method, from which 4 classes emerged, namely: Social network and change in the routine of informal caregivers during the COVID-19 pandemic period; Factors that interfere with the QoL of informal caregivers; How informal caregivers experience the Alzheimer's disease diagnosis; and Feelings awakened by the burden of informal caregivers of aged people with AD. **Results:** The female profile stood out, with emphasis on caregivers aged from 40 to 49 years old, married, incomplete High School, and performing this role for more than five years and full-time. The factors that interfere with quality of life are lack of time, care burden, lack of leisure, few social activities and feelings of sadness, anxiety, nervousness, depression and despair. **Conclusion:** It was verified that the aspects found were impacted even more during the COVID-19 pandemic period, which reconfigured the routine of older adults with Alzheimer's and of informal caregivers.

Descriptors: Alzheimer Disease; Caregivers; Aged; Coronavirus; Quality of Life.

Whats is already known on this?

The COVID-19 pandemic exerted a negative impact on caregivers' mental health, taking into account the lower quality of life referring to the Psychological domain.

What this study adds?

Informal caregivers acknowledge they need to improve their QoV and, even facing difficulties, seek to fit leisure into their routine, without impairing the health of older adults with Alzheimer's Disease.



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Resumo

Objetivo: Desvelar sobre a qualidade de vida dos cuidadores informais de idosos com Doença de Alzheimer em tempos de pandemia da COVID-19. **Método:** Estudo descritivo, qualitativo, por meio de entrevista semiestruturada com 12 cuidadores informais de idosos, selecionados por conveniência. O processamento dos dados foi realizado pelo software IraMuTeQ e análise das classes pelo método de Strauss e Corbin, da qual emergiram 4 classes: rede social e mudança na rotina dos cuidadores informais no período da pandemia da COVID-19; fatores que interferem na QV do cuidador informal; vivenciando o diagnóstico de Alzheimer pelo cuidador informal e sentimentos despertados pela sobrecarga dos cuidadores informais de idosos com DA. **Resultados:** O perfil feminino se sobressaiu, com destaque para cuidadores com idade entre 40 a 49 anos, casados, ensino médio incompleto, desempenhando esta função por mais de cinco anos e em tempo integral. Os fatores que interferem na qualidade de vida são a falta de tempo, sobrecarga do cuidado, falta de lazer, baixas atividades sociais e sentimentos de tristeza, ansiedade, nervosismo, depressão e desespero. **Conclusão:** Constatou-se que os aspectos encontrados foram impactados ainda mais durante o período da pandemia da COVID-19, que reconfigurou a rotina do idoso com Alzheimer e do cuidador informal.

Descritores: Doença de Alzheimer; Cuidadores. Idosos; Coronavírus; Qualidade de Vida.

Resumen

Objetivo: Revelar detalles sobre la calidad de vida de cuidadores informales de ancianos que padecen Mal de Alzheimer en tiempos de la pandemia de COVID-19. **Método:** Estudio descriptivo y cualitativo desarrollado por medio de entrevistas semiestruturada con 12 cuidadores informales de ancianos, seleccionados por conveniencia. Los datos se procesaron en el software IraMuTeQ y el análisis de las clases a través del método de Strauss y Corbin, del cual surgieron 4 clases: Redes sociales y cambios en la rutina de los cuidadores informales durante el período de la pandemia de COVID-19; Factores que interfieren en la CV de los cuidadores informales; De qué manera los cuidadores informales experimentan el diagnóstico de Mal de Alzheimer; y Sentimientos que genera la sobrecarga de los cuidadores informales de ancianos con MA. **Resultados:** El sexo femenino sobresalió entre los participantes, especialmente cuidadores de 40 a 49 años de edad, casados, con estudios secundarios incompletos, y que han desempeñado esta función por más de cinco años y con régimen de jornada completa. Los factores que interfieren en la calidad de vida son los siguientes: falta de tiempo, sobrecarga generada por las tareas de cuidado, falta de actividades de ocio, escasa actividad social y sentimientos de tristeza, ansiedad, nerviosismo, depresión y desesperanza. **Conclusión:** Se verificó que los aspectos encontrados se vieron incluso más afectados durante el período de la pandemia de COVID-19, que reconfiguró las rutinas de los ancianos que padecen Mal de Alzheimer y de los cuidadores informales.

Descriptor: Enfermedad de Alzheimer; Cuidadores; Anciano; Coronavirus; Calidad de vida..

INTRODUCTION

Currently, it is known that the number of aged individuals in Brazil tends to grow over the years. In 2075, the aged population is expected to reach a peak, with more than 79.2 million people aged at least 60 years old.^(1,2)

This scenario is accompanied by an increase in the incidence and prevalence of chronic degenerative diseases associated with aging. Among these pathologies, Alzheimer's Disease (AD) is of significant epidemiological relevance, accounting for 60% to 70% of all the cases of dementia in older adults.⁽³⁾

AD is a neurodegenerative disease characterized by progressive and continuous deterioration of nerve cells, which results in a decrease of various motor and cognitive functions. This leads to problems in memory, thinking and language, resulting in various financial impacts and burdens for the affected individuals.^(4,5)

Given this situation, there is a need to take care of older adults with AD and recognize the importance of caregivers in this process, especially informal caregivers. This role oftentimes arises informally, influenced by factors such as physical and affective proximity, less financial power, greater time availability, family pressure or the older adult's own choice,⁽⁶⁾ Due to chronicity of the disease, aged people will need care provided by another person, whether a family member or not, who assumes the responsibility of providing assistance in the face of the frailty and disability associated with AD.⁽⁷⁾ In Brazil, it is a cultural practice that caregivers of older adults are usually informal ones, that is, someone who performs this role without receiving any remuneration and without having undergone specific training.⁽⁸⁾ During the COVID-19 pandemic period, the demands resulting from AD caused greater burden of responsibilities for informal caregivers, impairing their Quality of Life (QoL).⁽⁹⁾

Thus, the restriction measures implemented imposed new challenges and stressors for informal caregivers, including the full-time care of older adults with AD and the need to add supplementary care to avoid contamination by COVID-19.⁽¹⁰⁾ This continuous care situation attributes several stressors to the care process, which have significant repercussions on the to the informal caregivers' demands referring to work, leisure and self-care. This can lead to a negative health perception, affecting both the physical and mental well-being of informal caregivers.⁽¹¹⁾

Thus, the COVID-19 pandemic imposed the need for containment and isolation of communities and individuals, resulting in feelings of fear, frustration and loneliness. This contributes to the decreased QoL perception of those who care for others, including informal caregivers.^(12,13)

This study is justified by the understanding that AD not only affects older adults' health, but also informal caregivers' QoL. In addition to that, the COVID-19 pandemic exerted a greater negative impact on the QoL of informal caregivers of AD patients. These caregivers faced more intense emotional, physical, economic and psychological stress levels. They dealt with aged people totally dependent on their functions, and the caregivers' advanced age also contributed to a negative impact on the QoL of these informal caregivers during the pandemic. In addition to that, these caregivers faced the challenge of living with and caring for older adults with AD full-time, in addition to facing difficulties or impossibility of sharing "care" with others due to the older adults' risk of contamination by COVID-19.⁽¹⁴⁾

In this sense, this study aims at unveiling the QoL of informal caregivers of aged people with AD in times of the COVID-19 pandemic.

METHODS

A descriptive study with a qualitative approach carried out with informal caregivers who participate in the Brazilian Alzheimer Association (*Associação Brasileira de Alzheimer*, ABRAZ), affiliated to the municipality of Belém, capital city of Pará, for which the Equator COREQ check-list was used.

Initially, the target population consisted of 22 participants; however, six did not meet the inclusion and exclusion criteria and four did not accept to take part in the research, resulting in a total of 12 participants. The sample was selected for convenience,⁽¹⁵⁾ considered as a non-probabilistic technique used to create non-random samples according to ease of access to the participants.

The inclusion criteria for the research were as follows: being an informal caregiver of an aged person with AD and having worked as the primary caregiver for at least six months. The exclusion criterion was difficulty accessing the Internet and communicating with the interviewer.

For data collection, a semi-structured interview script was used, carried out from November 14th, 2021 to February 10th, 2022. The interview script consisted of two blocks of questions. The first block was targeted at the sociodemographic characterization of the informal caregivers, including information such as name, age, gender, marital status, schooling, degree of kinship, hour load and care time. The second block of questions was comprised by open questions developed by the researchers, with the objective of knowing the aspects corresponding to the QoL of informal caregivers of older adults with AD.

Data collection was carried out through WhatsApp video, with the participants' authorization for video and audio recording. The interviews were scheduled according to each participant's availability, in order to respect their privacy and social distancing, aiming to obtain greater adherence from the target population.

Data analysis was performed using the Iramuteq (*Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires*) free software. After assembling the classes, the Strauss and Corbin analysis⁽¹⁶⁾ was used to carry out the conceptual sorting of the classes that were created. For this, the choice was Descending Hierarchical Classification (CHD)⁽¹⁷⁾ using a dendrogram, which allows regrouping the *corpus* elements according to their similarity to each other.

Discussion of the results was based on the classes generated in Iramuteq. This part of the research contains comments on the results, a comparison with previous studies and the author's opinion on the topic, in order to synthesize the most relevant findings on the theme.

For a better relationship between the classes, the frequencies and chi-square correlation values of each word in the *corpus* were calculated from the predefined frequency.⁽¹⁷⁾

In the research, inferential statistical methods were used, such as chi-square distribution (χ^2), in order to quantitatively evaluate the results observed in relation to the expected distribution of the phenomenon under study. Thus, it is possible to know the values generated and validated by the method presented.⁽¹⁸⁾

RESULTS

A total of 12 informal caregivers aged 40 to 76 years old took part in the study. Of the participants, 6 (50%) were aged between 40 and 49 years old, 3 (25%) between 60 and 69, 2 (16.7%) between 50 and 59 and 1 (8.3%) was 76 years old. In relation to gender, 10 (83.4%) were female and 2 (16.6%) were male. As for marital status, 3 (25%) were single, 6 (50%) married, 2 (16.67%) divorced and 1 (8.33%) lived in stable

relationships. Referring to schooling level, 10 (83.4%) caregivers had complete High School, 1 (8.3%) incomplete High School and 1 (8.3%) complete Higher Education. In relation to the degree of kinship, the data obtained were as follows: 9 (75.1%) were sons/daughters, 1 (8.3%) was a granddaughter, 1 (8.3%) was a niece and 1 (8.3%) was a husband. With regard to the care hour load, 10 (83.3%) provide full-time care and 2 (16.6%) part-time, being available 7 days a week. When asked how long they have been providing this care, 6 (50%) have been in this role for 5 to 10 years, 4 (33.33%) for 1 to 5 years, 1 (8.33%) for 10 to 15 years and 1 (8.33%) for 15 to 20 years.

As for the answers to the questions about QoL, they were transcribed in order to create a textual *corpus* for analysis in the IRaMuTeQ software. Subsequently, the words were categorized through DHC. The software identified a set of 12 texts in the full textual *corpus* and a set of 155 text segments (TSs).

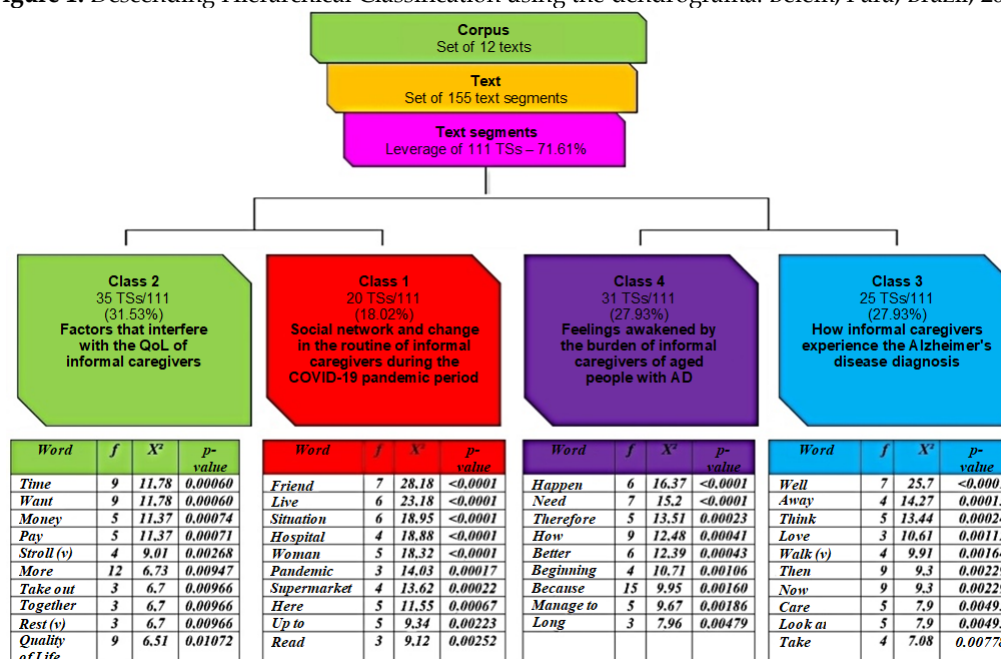
For analysis, 111 TSs were used, which represents approximately 71.61% of the total TSs in the *corpus*, considered adequate by the software. After the analysis, IRaMuTeQ generated 4 different classes. Class 1 represents 18.02% of the total TSs of the textual *corpus* used, Class 2 accounts for 31.53% of the TSs, Class 3 represents 22.52% and Class 4 includes 27.93% of the TSs.

In the association of the fixed variables, the following keywords were used: caregiver, age, gender and schooling.

The results are displayed in the form of different classes, taking into account their appearance frequency in the texts and their correlation. After analyzing the classes, they were named as follows: Class 1: Social network and change in the routine of informal caregivers during the COVID-19 pandemic period; Class 2: Factors that interfere with the QoL of informal caregivers; Class 3: How informal caregivers experience the Alzheimer's disease diagnosis; and Class 4: Feelings awakened by the burden of informal caregivers of aged people with AD.

These classes represent the main topics and aspects identified in the analysis of the texts. Figure 1 shows these classes.

Figure 1. Descending Hierarchical Classification using the dendrograma. Belém, Pará, Brazil, 2023.



Source: The authors (2023).

Social network and change in the routine of informal caregivers during the COVID-19 pandemic period

The first class addresses issues related to using social networks as a means for informal caregivers of older adults with AD to maintain socioaffective relationships during the COVID-19 pandemic. Some examples of testimonies that illustrate this class are included below:

I manage to keep in touch with my friends mainly with this WhatsApp and Facebook technologies (C3)

My brother lives in the United States, he talks via WhatsApp, he comes twice a year (C2)

These statements exemplify how social networks have been a useful tool for informal caregivers to connect with others and to obtain information and emotional support, especially during the COVID-19 pandemic.

In addition to that, the first class shows important changes in the routine of informal caregivers of aged people with AD during the pandemic. These changes include increased care with COVID-19 prevention measures, changes in family roles and frailty of the support network, described in the following statements:

There are friends of mine who are afraid to come here because of our advanced age (C4)

Only me, my daughter and my mother live here, the other people who come to my house are the formal caregivers and a day worker (C2)

My children that don't live here are afraid of contaminating us and bringing this disease into the house (C4)

I have some brothers that don't want to take care of our mother and our relationship is difficult, they don't want to be responsible (C8)

When they're bedridden [older adults], when they're in this stage, many relatives don't want to know, so there's not much bond (C5)

Our behaviors have changed due to this situation that the whole world has already improved, but we still have our restrictions [...] I bought sandals, the professionals [physiotherapists, speech therapists] leave the shoes outside (C2)

These statements reflect the challenges faced by informal caregivers during the pandemic, such as the need to adapt to new care routines, assume more responsibilities and deal with lack of support from the previously available support network.

Factors that interfere with the QoL of informal caregivers

In the data processing by IRaMuTeQ, it was observed that the most frequent words were "money", "strolling", "QoL" and "rest". Content analysis identified that informal caregivers of aged people with AD face weaknesses in QoL, resulting from lack of time to perform leisure and self-care activities, as the care routine for older adults with AD is considered exhausting, according to the statements below:

I don't have quality of life, I want to improve it, but the time I have, I want to rest, because time is very busy, I know I need to take time to take care of myself (C6)

I don't have any leisure, I take care of my mother all day long (C2)

I have to take time out to care for myself and improve quality of life, I have no leisure time, I work and take care of my mother from Sunday to Sunday, my life is here at home or going out to deliver cakes or pay bills (C6)

There are few times that I go out to relax, before I used to pick up my friends in the neighborhood [...], but now I just can't due to the state she is in, I have difficulty reconciling day-to-day activities (C9)

It's hard for me to have leisure time, I depend on someone else to be with her (C11)

This finding suggests that informal caregivers may face financial difficulties, restrictions on and outings in going for strolls, and difficulties finding time for rest and self-care. These factors contribute to informal caregivers' emotional and physical burden, negatively affecting their QoL.

How informal caregivers experience the Alzheimer's disease diagnosis

The words “away”, “think”, “care” and “love” were the most frequent in the third class identified by IRaMuTeQ and, although they may seem disconnected, when performing content analysis of the discussions, it was observed that the words were used in association with negative feelings attributed to AD.

The term “away” was used to express the feeling that the aged person with AD is distancing or leaving, that is, the perception that the older adult is “going away” or even dying.

The term “think” indicates certain weakness in knowledge about AD, in which much of what is known is based on guesswork and stereotypes. On the other hand, the terms “care” and “love” are related to the feeling of dedication and intensified care that informal caregivers give to older adults with AD. These terms highlight how this care is provided, that is, described as being done out of love, which can be better evidenced in the following phrases:

I'm a human being [...] I feel sadness, for example, you get irritated because the older adult with Alzheimer is repetitive, he asks a lot (C2)

I don't do more than my duty. I still think that it's little for what she did for me and I can only say that she's very lovingly cared for. When we care with love and give love, she knows, I see the gratitude in her eyes, there's no price (C6)

When that Alzheimer force comes and she gets agitated, I feel afraid I thought she'd go away. There are days when she gets very distressed and I can't sleep looking at her. I have a very bad feeling of seeing the person leaving (C10)

She welcomes me, there's love, a tune and that gives me warmth (C2)

These observations suggest that, even with the challenges and difficulties faced, informal caregivers dedicate themselves in a special way to the care of aged people with AD, driven by a feeling of love and the need to provide adequate care.

Feelings awakened by the burden of informal caregivers of aged people with AD

The fourth class shows the feelings awakened by the burden of informal caregivers of aged people with AD. This class revealed important expressions and feelings in the process of caring for older adults with AD, such as sadness, anxiety, nervousness, depressive symptoms and despair, as shown in the following statements:

Look, it happened that I cried and that's how I'll tell you why I cried, because I wanted to do something on the computer and I couldn't get it right, you know that the person who's older doesn't have Internet skills, those things (C2)

I keep oscillating between high and low, coming and going. There are times when I think it's easy, then I suddenly despair because it's tiring (C3)

Right at the beginning, I didn't take care of myself, I was going into depression and I had support beyond the ABRAZ, UNAMA psychology because my mother used to do speech therapy there (C5)

I get very sad and anxious, in agony and nervous; people talk to me and I get bored because the day-to-day is not easy [...] people tell me to take care of myself, that her disease will only get worse (C9)

These testimonies reveal the intense emotional and psychological burden faced by informal caregivers when caring for aged people with AD. Feelings of sadness, anxiety, nervousness, depressive symptoms and despair are common in this context, reflecting the impact of the care burden on informal caregivers' mental and emotional health.

DISCUSSION

Most of the informal caregivers were young, women and married, data similar to those found in the literature, evidencing the historical conception that the role of caring for family members is naturally assigned to women.⁽¹⁹⁾ As for schooling, most caregivers only have complete High School, which sometimes reinforces health literacy weakness. This is because caring for older adults with AD requires skills in reading and interpreting texts, prescriptions and guidelines, in addition to the impetus to seek information, make decisions and act on the part of caregivers.^(20,21)

Referring to the degree of kinship, 9 (75.1%) were sons/daughters; 1 (8.3%) was a granddaughter; 1 (8.3%) was a niece and 1 (8.3%) was a husband. These data are similar to those found in the literature, and are explained as being due to the feeling of duty and/or the financial difficulty hiring the services of a professional.⁽²²⁾

However, in addition to socioparental issues, the sentimental aspect is also related to this finding, given that proximity, coexistence, intimacy and living with the older adults with AD bring peers closer together.⁽²³⁾

With the data processing by the software, it was noticed that, during the pandemic, informal caregivers of aged people with AD were of paramount importance due to the older adults' increased vulnerability in relation to the disease, considering the distancing and isolation measures. However, this emphasizes a current reality: the social isolation of older adults and informal caregivers, who take care of the sick aged person on their own.⁽²⁴⁾

Regarding the time spent caring for older adults with AD, it is shown that most informal caregivers have a family bond and, therefore, assume the role of caregiver, even without preparation, from an early age and perform it for extended periods of time.⁽²⁵⁾ It is noted that informal caregivers of older adults with AD are mostly wives or sons/daughters⁽²⁶⁾, due to feelings of gratitude and duty.⁽²⁷⁾

In relation to the hour load, the data from this study show that 10 (83.3%) provide full-time care and that 2 (16.6%) do so part-time, being available 7 days a week. In addition, when questioned about the time they have provided this care, it was found that 6 (50%) have been in this role for 5 to 10 years, 4 (33.33%) for 1 to 5 years, 1 (8.33%) for 10 to 15 years and 1 (8.33%) for 15 to 20 years. These findings are similar to those found in the literature, where 50 informal caregivers reported providing care for approximately 8.7 years and devoting approximately 17.5 hours a day during the pandemic period.⁽²⁸⁾ This evidences that caring for aged people with some dependence degree is intense and a predisposing factor for burden, leaving little or no time for leisure and/or self-care activities.⁽²⁹⁾

In addition to that, the changes imposed by COVID-19 on the routine of informal caregivers of aged people with AD became the subject of discussions, due to the new challenges caused by the pandemic. Above all, the imposition of distancing between peers as a way of protecting older adults, considered vulnerable to illness, contributed to reports of decreased QoL among informal caregivers.^(30,31,32)

The results of this study showed that the pandemic intensified a very current problem: Family Dysfunction. It is verified that the COVID-19 pandemic intensified distancing between family members, which already existed, in addition to reducing or canceling visits to older adults; and violence against aged people was increased in its various categories. This caused an important change in family dynamics and a consequent decrease in the responsible informal caregivers' QoL, mainly because it impaired their physical and emotional state.⁽³³⁾ In this regard, a study showed the positive impact of social media as an alternative measure to approach older adults during the COVID-19 pandemic. These platforms enabled follow-up in times of social isolation, allowing approximation and strengthening of the caregivers' support network.⁽³⁴⁾

The changed routine raised concerns about the biosafety measures to prevent contamination in older adults, especially because aged people with cognitive impairment were more likely to be contaminated due to the difficulty remembering and following the guidelines given by the World Health Organization (WHO).⁽³⁵⁾ From this perspective, a new universe was created with different day-to-day responsibilities resulting from the process of caring for older adults with dementia, especially during the COVID-19 pandemic.⁽³⁶⁾

How informal caregivers experience the Alzheimer's disease diagnosis is an important finding. The informal caregivers' perception in seeing the older adults "go away" refers to the patients' depersonalization, and the presence of "Anticipated Mourning" is used to express the adaptation process to an announced loss. This explains the depression and burden evidenced by informal caregivers of demented patients.⁽³⁷⁾ The weakness of health education exerts a direct impact on the older adults affected by the disease and on their support network, especially on family composition. They are faced with an

increase in frailty, including gaps in knowledge and proper management of aged people with AD, even by health professionals themselves.⁽⁹⁾

This situation is aggravated by the fact that AD has no cure and is a disease still unknown by the population. The difficulties start from the diagnosis and extend to care provision. The caregivers receive incipient information from health professionals about the entire course of the disease and are faced with a new, limiting and unsafe situation.⁽⁹⁾ It is understood that health professionals should take ownership of the AD causes and peculiarities in order to be able to guide, educate and offer emotional support to the people taking over the care to be provided, even if informally, to aged people with AD.⁽³⁸⁾

Still on this, the ABRAZ plays an important role in improving informal caregivers' QoL, as it contributes by disseminating diverse information, explanations and support. The organization provides explanations about the disease, as well as about its symptoms and side effects, thus improving the QoL of those involved in the care process.⁽³⁹⁾

Despite the dedication to older adults, it cannot be denied that the negative expressions experienced by informal caregivers are due to the care burden. Culturally, in Brazil care for older adults is attributed to an informal support network, where there is no adequate training. It is care that is provided without remuneration or training, based on the proximity between caregivers and aged people, and which results in a new reality, oftentimes arduous and stressful, compromising the biopsychosocial state.^(31,40)

In view of this, it is important to consider the factors that condition depression, such as the absence of activities that involve social interaction, leisure and physical exercises.⁽⁴¹⁾ A research study showed that the main complaints of caregivers of older adults during the COVID-19 pandemic were fear, anxiety, stress and loneliness, related to the intense care modality and to lack of social support. They prioritize older adults to the detriment of their own care, which contributes to the feeling of burden.⁽⁴²⁾

Similar results to those in this study were found in the literature. In the first place, a study analyzed informal caregivers of older adults in relation to the burden and psychological distress resulting from the social isolation obligation during the COVID-19 pandemic. It was observed that prevalent depression and anxiety symptoms were found in people who informally cared for and lived with older adults during the pandemic.⁽²⁸⁾ Another survey showed that the COVID-19 pandemic impacted the QoL of informal caregivers of aged people with dementia, with depression and anxiety symptoms associated with the feeling of burden.⁽⁴³⁾

With the need for social distancing due to the COVID-19 pandemic, participation in backup and/or support groups offers caregivers a way to reduce the feeling of loneliness.⁽³⁵⁾

This study is limited by a small sample of informal caregivers due to the difficult access to these people as a result of their daily responsibilities. However, as a contribution, the study identified biopsychosocial aspects that influence QoL and suggested that Nursing can seek strategies to overcome such difficulties. In addition to that, leisure practices were identified that can help reduce the difficulties faced by informal caregivers while providing care to aged people with AD.

CONCLUSION

The results of this study made it possible to identify that, given the social dimensions and considering physical and emotional health, as well as personal relationships, informal caregivers, who are usually family members, especially the sons/daughters, become the main care reference for older adults with AD. The female profile stood out, with emphasis on caregivers aged from 40 to 49 years old, married, with incomplete High School, and performing this role for more than five years and full-time.

It is revealed that informal caregivers' QoL is strongly associated with a feeling of burden, physical and emotional fatigue, reduced self-care, lack of leisure, withdrawal from religious practices and financial difficulties. It was found that these aspects were impacted even more during the COVID-19 pandemic period, which reconfigured the routine of older adults with AD and of their informal caregivers.

However, aged people's susceptibility to the COVID-19 disease, added to the perception that social isolation was an aggravating factor, resulted in weakening of the support network and lack of interest among other family members and entities in supporting care for older adults with AD. It is noted that informal caregivers acknowledge that they need to improve their QoL and, even facing difficulties, they seek to fit leisure activities into their routines, without compromising the health of older adults with AD.

CONTRIBUTIONS

Contributed to the conception or design of the study/research: Nascimento MTA, Carvalho DNR, Bendelaque DFR, Sousa FJD, Orlandi FS, Aguiar VFF. Contributed to data collection: Nascimento MTA, Carvalho DNR, Bendelaque DFR, Sousa FJD, Aguiar VFF. Contributed to the analysis and/or interpretation of data: Nascimento MTA, Carvalho DNR, Bendelaque DFR, Sousa FJD, Aguiar VFF. Contributed to article writing or critical review: Nascimento MTA, Bendelaque DFR, Sousa FJD, Orlandi FS, Lima FC, Aguiar VFF. Final approval of the version to be published: Carvalho DNR, Sousa FJD, Orlandi FS, Lima FC, Aguiar VFF.

REFERENCES

1. Vollset SE, Goren E, Yuan CW, Cao J, Smith AE, Hsiao T, et al. Fertility, mortality, migration, and population scenarios for 195 countries and territories from 2017 to 2100: a forecasting analysis for the Global Burden of Disease Study, *The Lancet*. [Internet]. 2020 July 14 [cited 2022 out. 10]; 396: 1285–306. Available from: [https://www.thelancet.com/article/S0140-6736\(20\)30677-2/fulltext](https://www.thelancet.com/article/S0140-6736(20)30677-2/fulltext).
2. Ripple WJ, Wolf C, Newsome TM, Barnard P, Moomaw WR. World Scientists' Warning of a Climate Emergency, *BioScience*, [Internet]. 2020 Jan; 70(1): 8–12. Doi: <https://doi.org/10.1093/biosci/biz088>
3. Echeverría A, Astorga C, Fernández C, Salgado M, Villalobos Dintrans P. Funcionalidad y personas mayores: ¿dónde estamos y hacia dónde ir?. *Rev Panam Salud Publica*. [Internet]. 2022 Apr 14; 46:e34. Available from: Doi: <https://doi.org/10.26633/RPSP.2022.34>
4. Marques YS, Casarin F, Huppés B, Maziero BR, Gehlen MH, Ilha S. Doença de alzheimer na pessoa idosa/família: potencialidades, fragilidades e estratégias. *Cogitare Enferm* [Internet]. 2022;27:e80169. Doi: <https://doi.org/10.5380/ce.v27i0.80169>
5. Lynch C. World Alzheimer Report 2019: Attitudes to dementia, a global survey. *Alzheimers dememt*. 2020 Dec 7; 16(Supl.10):e038255 Doi: <https://doi.org/10.1002/alz.038255>.
6. Moreira ML, Bucher-Maluschke JSNF, Silva JC, Falcão DVS. Cuidadores informais de familiares com Alzheimer: vivências e significados em homens. *Contextos Clínicos* 2018; 11(3): 373-85. <https://dx.doi.org/10.4013/ctc.2018.113.08>.
7. Dadalto EV, Cavalcante FG. O lugar do cuidador familiar de idosos com doença de Alzheimer: uma revisão de literatura no Brasil e Estados Unidos. *Ciênc saúde colet*. 2021 Jan; 26(1):147-57. Doi: <https://doi.org/10.1590/1413-81232020261.38482020>.
8. Sanches R de CN, Santos FTG, Radovanovic CAT. Construção e validação de questionário para avaliação das competências do cuidador informal. *Cogitare Enferm* [Internet]. 2021 Nov 22;26:e73966. Doi: <https://doi.org/10.5380/ce.v26i0.73966>.
9. Costa EMDMC, Lucena MM, Estrela YCA, Oliveira Neto HT, Brito EPR, Rezende ACC, et al. Impactos na qualidade de vida de cuidadores de idosos portadores de Alzheimer. *Braz Jour Heal Rev*. [Internet]. 2021;4(2): 7726 - 41. Doi: <https://doi.org/10.34119/bjhrv4n2-309>.
10. Hammerschmidt KSA, Santana RF. Saúde do idoso em tempos de pandemia Covid-19. *Cogitare enferm*. [Internet]. 2020 Apr;25:e72849. <https://dx.doi.org/10.5380/ce.v25i0.72849>.
11. Nardi EFR, Sawada NO, Santos JLF. Associação entre a incapacidade funcional do idoso e a sobrecarga do cuidador familiar. *Rev. Latino-Am Enfermagem*. 2013 Sept-Oct; 21(5): 1-8. Doi: <https://doi.org/10.1590/S0104-11692013000500012>.
12. Peçanha T, Goessler KF, Roschel H, Gualano B. Social isolation during the COVID-19 pandemic can increase physical inactivity and the global burden of cardiovascular disease. *Am J Physiol Heart Circ Physiol* [Internet]. 2020 May 20; 318(6): H1441–6. Doi: <https://doi.org/10.1152/ajpheart.00268.2020>.

13. Rezende CP, Nascimento MMG, França AP, Santos ASA, Oliveira IV, Oliveira DR. Caring for elderly people during the COVID-19 pandemic: the experience of family caregivers. *Rev Gaúcha Enferm* [Internet]. 2022;43:e20210038. Doi: <https://doi.org/10.1590/1983-1447.2022.20210038.en>.
14. Garcia CR, Cipolli GC, Santos JP dos, Freitas LP, Braz MC, Falcão DV da S. Cuidadores Familiares de Idosos com a Doença de Alzheimer. *Kairós-Gerontologia* [Internet]. 30º de março de 2017 [citado 10º de julho de 2023];20(1):409-26. Disponível em: <https://revistas.pucsp.br/index.php/kairos/article/view/2176-901X.2017v20i1p409-426>.
15. Casal J, Mateu E. Tipos de Muestreo. *Rev. Epidem. Prev. Med.* 2003; [cited 2023 jan. 10];1(1):3-7. Available from: <https://www.coursehero.com/file/9890875/TiposMuestreo1>
16. Patias ND, Hohendorff JV. Critérios de qualidade para artigos de pesquisa qualitativa. *Psicol Estud* [Internet]. 2019;24:e43536. Available from: Doi: <https://doi.org/10.4025/psicolestud.v24i0.43536>
17. Souza MAR, Wall ML, Thuler ACMC, Lowen IMV, Peres AM. The use of IRAMUTEQ software for data analysis in qualitative research. *Rev Esc Enferm USP.* 2018;52:e03353.. Available from: <http://dx.doi.org/10.1590/S1980-220X2017015003353>
18. Klant LM, Santos VS. O uso do software IRAMUTEQ na análise de conteúdo - estudo comparativo entre os trabalhos de conclusão de curso do ProfEPT e os referenciais do programa. *RSD.* 2021; 10(4): e8210413786: 1-15. Doi: <https://doi.org/10.33448/rsd-v10i4.13786>.
19. Santos FGT, Zulin A, Cardoso LCB, Sanches RCN, Rego AS, Girardon-Perlini NMO, et al. Factors associated with the skills of informal caregivers in home care. *Rev Bras Enferm.* 2022; 75(4): e20210744. Available from: Doi: <https://doi.org/10.1590/0034-7167-2021-0744>.
20. Anjos ZS, Lohmann PM, Medeiros CRG, Brietzke AP. Assistência de enfermagem na doença de Alzheimer: uma revisão integrativa. *RSD* [Internet]. 2022 May 28 [cited 2022 nov 11];11(7):e37911728874. Available from: <https://rsdjournal.org/index.php/rsd/article/view/28874>.
21. Queiroz JPC, Machado ALG, Vieira NFC. Health literacy for caregivers of elders with alzheimer's disease. *Rev Bras Enferm* [Internet]. 2020;73:e20190608. Doi: <https://doi.org/10.1590/0034-7167-2019-0608>
22. Martins G, Corrêa L, Caparrol AJS, Santos PTA, Brugnera LM, Gratão ACM. Sociodemographic and health characteristics of formal and informal caregivers of elderly people with Alzheimer's Disease. *Esc Anna Nery* [Internet]. 2019;23(2):e20180327. Doi: <https://doi.org/10.1590/2177-9465-EAN-2018-0327>.
23. Queiroz RS, Camacho ACLF, Gurgel JL, Assis CRC, Santos MLSC. Perfil sociodemográfico e qualidade de vida de cuidadores idosos com demência. *Rev Bras Geriatr Gerontol* [Internet]. 2018 Apr/Mar; [cited 2018 Sep]; 21(2):205-14. Available from: http://www.scielo.br/scielo.php?pid=S1809-98232018000200205&script=sci_arttext&tlng=pt.
24. Silva MF, Silva DSM, Bacurau AGM, Francisco PMSB, Assumpção D, Neri AL, et al. Ageism against older adults in the context of the COVID-19 pandemic: an integrative review. *Rev Saúde Pública* [Internet]. 2021;55:4. Doi: <https://doi.org/10.11606/s1518-8787.2021055003082>.
25. Lopes CC, Oliveira GA, Stigger FS, Lemos AT. Associação entre a ocorrência de dor e sobrecarga em cuidadores principais e o nível de independência de idosos nas atividades de vida diária: estudo transversal. *Cad. saúde colet.* 2020 Jan-Mar; 28(1):98-106. Doi: <https://doi.org/10.1590/1414-462X202028010184>.

26. Barbosa IEB, Mota BS. O impacto na qualidade de vida do cuidador do idoso com doença de alzheimer. *Rev. Enferm. Atual In Derme* [Internet]. 2023 Feb 8 [cited 2023 May 05];97(1):e023020. Available from: <https://www.revistaenfermagematual.com.br/index.php/revista/article/view/1562>.
27. Batista IB, Marinho JS, Brito TRP, Guimarães MSA, Silva Neto LS da, Pagotto V, et al. Qualidade de vida de cuidadores familiares de pessoas idosas acamadas. *Acta paul enferm* [Internet]. 2023;36:eAPE00361. Doi: <https://doi.org/10.37689/acta-ape/2023AO00361>.
28. Silva GDO, Martins G, Rocha LA, Machado MT, Pott Junior H, Gratão ACM. Sobrecarga e sintomas psicológicos em cuidadores informais de idosos na pandemia da COVID-19. *Rev Gaúcha Enferm* [Internet]. 2022 Nov 21 [cited 2023 May 8];43(ESP). Available from: <https://seer.ufrgs.br/index.php/rgenf/article/view/128590>.
29. Gaioli CCLO, Furegato ARF, Santos JLF. Perfil de cuidadores de idosos com a doença de Alzheimer associado à resiliência. *Texto contexto-enferm*. 2012 Mar; 21(1): 150-7. Doi: <https://doi.org/10.1590/S0104-07072012000100017>.
30. Anjos KF, Boery RNSO, Pereira R, Pedreira LC, Vilela ABA, Santos VC, et al. Associação entre apoio social e qualidade de vida de cuidadores familiares de idosos dependentes. *Ciênc. saúde coletiva*. 2015 May; 20(5):1321-30. Doi: <https://doi.org/10.1590/1413-81232015205.14192014>.
31. Couto AM, Castro EAB, Caldas CP. Vivências de ser cuidador familiar de idosos dependentes no ambiente domiciliar. *Rev Rene* [Internet]. 2016 Feb 21; [cited 2023 May 4];17(1):76-5. Available from: <http://www.periodicos.ufc.br/rene/article/view/2624>.
32. Mattos EBT, Francisco I da C, Pereira GC, Novelli MMPC. Grupo virtual de apoio aos cuidadores familiares de idosos com demência no contexto da COVID-19. *Cad Bras Ter Ocup* [Internet]. 2021;29:e2882. Doi: <https://doi.org/10.1590/2526-8910.ctoRE2201>
33. Souza LJ, Farias RCP. Violência doméstica no contexto de isolamento social pela pandemia de covid-19. *Serv Soc Soc* [Internet]. 2022 May; (144):213–32. Doi: <https://doi.org/10.1590/0101-6628.288>.
34. Banskota S, Healy M, Goldberg EM. 15 Smartphone apps for older adults to use while in isolation during the COVID-19 Pandemic. *West J Emerg Med*. 2020;21(3):514–25. Doi: <https://doi.org/10.5811/westjem.2020.4.47372>.
35. Huali W, Li T, Barbarino P, Gauthier S, Brodaty H, Molinuevo JL et al. Dementia care during COVID-19. *The Lancet*. 2020 Apr 11; 395:10231:1190-91. [http://dx.doi.org/10.1016/S0140-6736\(20\)30755-8](http://dx.doi.org/10.1016/S0140-6736(20)30755-8).
36. Holmes EA, O'Connor RC, Perry VH, Tracey I, Wessely S, Arseneault L, et al. Multidisciplinary research priorities for the COVID-19 pandemic: a call for action for mental health science. *The Lancet Psychiatry*, [Internet]. 2020 Apr 15; 7(6): 547-560. [http://dx.doi.org/10.1016/S2215-0366\(20\)30168-1](http://dx.doi.org/10.1016/S2215-0366(20)30168-1).
37. Mattos EBT, Kovács MJ. Doença de Alzheimer: a experiência única de cuidadores familiares. *Psicol USP*. 2020; 31:e180023. Doi: <https://doi.org/10.1590/0103-6564e180023>.
38. Andrade SMB, Marinho MS, Santana ES, Chaves RN, Oliveira AS, Reis LA. Associação entre os aspectos sociodemográficos, condições de saúde e qualidade de vida dos cuidadores de idosos dependentes. *Fisioter. Bras*. 2019 Oct 24; 20(5). Doi: <https://doi.org/10.33233/fb.v20i5.2385>.
39. Rabelo ES, Lopes SC. A DEMÊNCIA NA TERCEIRA IDADE: a família no enfrentamento da doença, tendo como referência a ABRAZ de São Luís, MA. *Rev. Bibliomar* [Internet]. 2018;16(2):7-28. Disponível em: <https://periodicoeletronicos.ufma.br/index.php/bibliomar/article/view/8806>.

40. Dias ES, Moura HFS, Tannus CDA, Pacheco MP, Lemos GVL, Soares MIS, et al. Conflitos emocionais em cuidadores de pacientes com doença de alzheimer. *Braz. J. Develop.* [Internet]. 2020 May 19 [cited 2023 May 5];6(5):29036-50. Available from: <https://ojs.brazilianjournals.com.br/ojs/index.php/BRJD/article/view/10285>.
41. Scherrer G, Okuno MFP, Oliveira LM, Barbosa DA, Alonso AC, Fram DS, et al. Quality of life of institutionalized aged with and without symptoms of depression. *Rev Bras Enferm* [Internet]. 2019;72:127-33. Doi: <https://doi.org/10.1590/0034-7167-2018-0316>.
42. Nunes DP, Silva MJ, Brilhante BI, Ferreira CFY, Batello VVATG, Santos SSJ. et al. Apoio emocional a cuidadores de idosos: vivência de voluntários do projeto escuta solidária. *Cap. Dour.: Dial. Ext.* [Internet]. 2020 May 30[cited 2023 May 8];3(2):199-208. Available from: <https://sistemas.uft.edu.br/periodicos/index.php/capimdourado/article/view/9799>.
43. Ughes MC, Liu Y, Baumbach A. Impact of COVID-19 on the health and well-being of informal caregivers of people with dementia: a rapid systematic review. *Gerontol Geriatr Med.* 2021;7:23337214211020164. Doi: <https://doi.org/10.1177/23337214211020164>.

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