

Experience Report

Virtual support group for family caregivers of elderly people with dementia in the COVID-19 scenery

Grupo virtual de apoio aos cuidadores familiares de idosos com demência no contexto da COVID-19¹

Emanuela Bezerra Torres Mattos^a , Isabela da Costa Francisco^a ,
Gabrielle Christine Pereira^a , Marcia Maria Pires Camargo Novelli^a 

^aUniversidade Federal de São Paulo – UNIFESP, São Paulo, SP, Brasil.

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Abstract

Introduction: The physical, mental and social status of family caregivers and their care demands have been largely overlooked. This fact has been no different during the COVID-19 pandemic. Therefore, home care will need updates for this new pandemic context, prioritizing the provision of personalized guidance for family caregivers. **Objective:** To minimize the impact on the mental health of family caregivers of people with dementia through the virtual support group for family caregivers. **Method:** The research was developed from the performance of support groups for family caregivers in dementia in the virtual format. The meetings were weekly, lasting 2 hours and the themes were worked out according to the group's demands. All meetings were recorded, transcribed, and analyzed using thematic content analysis. **Results:** In the 8 meetings, 10 family caregivers participated and 5 thematic categories were identified: technology; the routine in the COVID-19 pandemic; behavioral changes and their relationship with the caregiver's mental health; the support network as a health marker; and the new way of carrying out meaningful activities. **Conclusion:** The support group in the virtual format proved to be a powerful tool for accessing information and guidance concerning dementia, about family care and actions aimed at the caregiver's self-care, with an impact on their emotional state and well-being, minimizing the feeling of social isolation during the COVID-19 pandemic.

¹ This work is the result of an extension project entitled Grupo Mente Aberta (Open Mind Group) of support family caregivers of people with dementia, offered by the Universidade Federal de São Paulo, Campus Baixada Santista. The contribution is original and unpublished, and has not been submitted to any other journal. We respected all the necessary ethical procedures in the analysis of the intervention.

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Keywords: Aging, Dementia, Caregivers, Occupational Therapy.

Resumo

Introdução: O estado físico, mental e social dos cuidadores familiares e as suas demandas no cuidado têm sido amplamente esquecidos. Este fato não tem sido diferente durante a pandemia da COVID-19. Portanto, o cuidado domiciliar precisará de atualizações para esse novo contexto da pandemia, priorizando fornecer orientações personalizadas para os cuidadores familiares. **Objetivo:** Minimizar o impacto sobre a saúde mental dos cuidadores familiares de pessoas com demência por meio do grupo virtual de apoio aos cuidadores familiares. **Método:** A pesquisa foi desenvolvida a partir da realização de grupos de apoio aos cuidadores familiares na demência no formato virtual. Os encontros foram semanais, com duração de 2 horas, e os temas eram trabalhados a partir das demandas do grupo. Todos os encontros foram gravados, transcritos e analisados por meio da análise de conteúdo temática. **Resultados:** Nos 8 encontros, participaram 10 cuidadores familiares e foram identificadas 5 categorias temáticas: a tecnologia; a rotina na pandemia da COVID-19; alterações de comportamento e sua relação com a saúde mental do cuidador; a rede de apoio como um marcador de saúde; e a nova forma de realizar as atividades significativas. **Conclusão:** O grupo de apoio no formato virtual se mostrou como uma ferramenta potente para o acesso à informação e para orientações em relação à demência, sobre o cuidado ao familiar e ações voltadas para o autocuidado do cuidador, com impacto no seu estado emocional e bem-estar, minimizando o sentimento de isolamento social durante a pandemia da COVID-19.

Palavras-chave: Envelhecimento, Demência, Cuidadores, Terapia Ocupacional.

Introduction

COVID-19 arrives in Brazil and has its first confirmed case on February 26, 2020, in São Paulo (Ministério da Saúde, 2020). As a measure to prevent the spread of the disease and the contagion curve, the authorities determined physical distance as an effective and necessary practice to stop increasing the cases in the country (Pan American Health Organization, 2020).

In general, older people are more vulnerable to natural disasters and we could identify this vulnerability during the COVID-19 pandemic (Kontoagelos et al., 2020), as it brings a greater risk of death in the older population with comorbidities, being a double problem for people living with dementia and their families and/or caregivers (Bianchetti et al., 2020; Huali et al., 2020).

Dementia, defined as Major Neurocognitive Disorder (MCD), has also been an important global public health problem with social and medical challenges (American Psychiatric Association, 2014; Engedal & Laks, 2016). Dementia syndromes are diagnosed from a cognitive decline (attention; executive functioning; learning and memory; language; motor perception and social cognition) according to a previous level of functional and occupational performance, reinforced by the individual's report, by an informant, or by clinical

observation⁶. It is estimated that the number of people with dementia worldwide will reach 65.7 million in 2030 and 115.4 million in 2050. In those years, this proportion will reach 63% and 71% in low- and middle-income countries (Prince et al., 2013).

In this period of physical distance, people with dementia deserve special attention, because, in addition to their need for help and/or supervision in activities of daily living, depending on the degree of impairment, they start to depend on others for the necessary care for preventing contamination of the coronavirus, as in the following cases: use of the mask, asepsis of the hands and social distance. This is due to their difficulty in retaining or processing new information, which implies greater risks of contracting the disease (Huali et al., 2020; Schapira et al., 2020). Many of these older people are dependent on third parties to guarantee access to food, medication, and other demands (Armitage & Nellums, 2020).

The gradual, progressive, and irreversible process of dementias compromise not only the people with dementia but also their caregivers and their family (Levy & Burns, 2011). Most of the time, they are women, old, and suffer significant overload and stress, with a tendency to gradually increase the demands and responsibilities as the disease progresses, which results in worse physical and psychological conditions (Mattos & Kovács, 2020), and implies greater susceptibility to abuse of the older person (Holmes et al., 2020), which can be exacerbated during physical distance.

According to Chan et al. (2020), the physical, mental, and social status of family caregivers and their care demands have been largely overlooked. This fact has not been different during the COVID-19 pandemic, in which there is a lack of knowledge about the situation due to the difficulty in accessing information, assistance, and medical guidance. Therefore, home care will need updates for this new pandemic context, providing personalized guidance for family caregivers.

Thus, Alzheimer's Disease International (2019) calls attention to the urgency of implementing psychosocial support networks and free support to minimize the impact on mental health, both of people with dementia and their caregivers, reducing stress, and using virtual means of attendance. Thus, this study aimed to minimize the impact on the mental health of family caregivers of people with dementia, through a virtual support group for family caregivers.

Method

The research was developed from eight meetings of the support group for family caregivers of older people with dementia, in virtual format due to the pandemic scenario of COVID-19.

The study was submitted to and approved by the Research Ethics Committee with human beings at the Universidade Federal de São Paulo, under opinion 0709/2018. In their first meeting, all participants received along with the meeting participation link, the Informed Consent Term (ICF) link, following Resolution 466/2012, for science and clarification of the objectives of the research, as well as ethical principles.

The support group for caregivers was offered in a virtual format due to the COVID-19 pandemic. There is a growing demand from caregivers for support and guidance from professionals in the Cognitive Aging Care Service (*SAEC Serviço de Atenção ao Envelhecimento Cognitivo*) at the Universidade Federal de Paulo/Campus Baixada Santista, for the care demands of the person with dementia and the self-care of the family caregiver.

The meetings with the group were through the virtual platform Google Meets. For this, caregivers received the link to the meeting via WhatsApp, with a pre-established day and time. The meetings were weekly, lasting 2 hours, and took place from 20/05/2020 to 07/07/2020.

The inclusion criteria for caregivers were exercising the role of family caregiver for at least 6 months; being a family caregiver for an older person with dementia and having an interest and availability to participate in the meetings. The exclusion criterion was to be a professional caregiver. To guarantee the ethical principle of secrecy and non-identification, all caregivers were identified with the acronym C, which corresponds to the caregiver, followed by a numeral from 1 to 10, according to the order of the statements presented.

The meetings were organized for the caregivers to highlight the themes they would like to address and discuss in the conversation circles. Occupational therapists, as coordinators of the group, aligned the aspects expressed by the participants to the central topic in the care of the other and of themselves. According to Morin (2003), the conversation circles, from the point of view of complexity, connect to separate issues, so that parts and the whole are captured as facets of the same object, which is complex and contradictory, hard and utopian: “the social conditions and the reality to be (re) constructed”.

At the meetings, the central issues of the discussions were the presentation of the participants (for the collection of sociodemographic data, general information regarding the health of the person with dementia and their caregiver) and other issues according to the demands of the caregivers (context of care, impact of pandemic, support networks and access to information and guidance).

All meetings were recorded, transcribed and, subsequently, analyzed through the analysis of thematic content proposed by Minayo (2015). The method presupposes a comprehensive reading of the material selected for the impregnation of the speeches, the exploration of the material to reach from the revealed to the veiled, and elaboration of an interpretative synthesis articulating central themes. From the analysis of the speeches, six thematic categories emerged that will be discussed in the following results.

Results and Discussion

Table 1 shows the results of the sociodemographic data of family caregivers participating in the support group.

Table 1: Sociodemographic data of participating family caregivers.

Participants	Age (years old)	Gender	Marital Status	Kinship Degree
C1	75	Female	Married	Partner
C2	68	Female	Married	Partner
C3	70	Male	Married	Partner
C4	47	Female	Divorced	Daughter
C5	20	Female	Single	Grand-daughter
C6	49	Male	Single	Son
C7	63	Female	Single	Daughter
C8	51	Male	Married	Son
C9	55	Female	Married	Daughter
C10	61	Female	Single	Daughter

Source: Own elaboration

During the eight meetings, approximately six family caregivers per group participated, and the total study participants were 10 family caregivers. Of these, 70% were female. The degree of kinship with the highest representation was son/daughter with 60%, followed by partners with 30%. The age of the caregivers ranged between 20 and 75 years old.

The caregiver C4 received support from the family in caring for the older person with dementia, while caregiver C7 received support in care through a professional caregiver. The others did not have a family support network, or professional caregivers, or the community during this period. Caregivers C4 and C10 took care of both parents, with one taking care of the mother with dementia and the father with Parkinson's disease, and the other taking care of the mother with dementia and the father over 90 years old, respectively. Only caregiver C8 did not live with his relative with dementia and caregiver C5 moved to his grandmother's house to help with care during the COVID-19 pandemic period.

Each meeting started with the questioning about the caregivers' routine, in which we identified the demands and all participants had the opportunity to talk about the topics according to the group's interest. From the demands presented, informative actions were taken on the care that permeates dementia and/or conversation circles on the topics covered. Based on the transcriptions and analysis of the speeches, we identified, presented, and discussed 5 thematic categories.

1st - Technology: advances and challenges

The arrival of COVID-19 and the need for social distancing led to a series of adjustments and reorganizations in the daily lives of individuals. As stated by Schapira et al. (2020), being at home these days is not comparable to being at home before the pandemic, and interaction with the outside world aims to be mediated by technology. It is WhatsApp messages, meetings, classes, lives through the videoconference platforms that go through the routine in an attempt to reconcile demands and obligations. Also, the difficulties with the use of various technologies were

limitations arising from the use of mobile devices and/or equipment, such as older computers and in previously unexplored functions (use of video calling), and also good quality internet access.

The virtual meetings showed some of the difficulties in the search for online support, as shown in the following reports:

I get a little confused here with these things. Am I showing up now?" and "how is it? It's just that it cuts a lot, I'm not understanding what you say, the connection is not good. (C1 (wife, 75 years old).

This internet is driving me crazy today. Here I'm not listening to you anymore. (C10, daughter, 61 years old).

Also, we observed how the environment in which the activity is carried out directly affects its results. The support group in the virtual format affected the level of involvement, attention, and time for themselves since many of the caregivers share the same space as their family members with dementia. We noticed the difficulty in maintaining a space of privacy for their speeches and needs.

So, he forgets, but it is normal ... I am in a meeting [answering someone in the background]. He is here in the room; he wants to know what I am talking about and why I am talking. (C2, wife, 68 years old).

The crossing of routine activities and overlapping tasks meant that some were unable to organize in advance for effective group participation.

Also, these groups are extremely important for family caregivers due to physical distancing. According to Camacho et al. (2020), informal support for family caregivers, through remote platforms in the pandemic period, is essential due to the need for singular guidance to care for the older person with cognitive impairments. But also, not only for them, as it is essential to provide a space for care and active listening to these family caregivers who constantly deal with the challenges of care in the physical distance with higher levels of overload and stress.

By stimulating the participation of family caregivers in these virtual spaces, access to information and guidance regarding the demands of care in dementia is allowed, at the same time as it favors the exchange of experiences and knowledge, a space for listening and welcoming (Camacho et al., 2020).

2nd - The reality of routine in the COVID-19 pandemic

The stimulation of the person with dementia in quarantine, the overlapping of tasks, the fear of contamination of oneself and the other, the greater vulnerability of their family members in the face of the COVID-19 pandemic are part of the daily routine of caregivers. According to the study by Bezerra et al. (2020), on the factors associated with the behavior of the population during physical distance in the COVID-19 pandemic, for 39% of respondents, social interaction is the main aspect that is being affected by the distance. Brooks et al. (2020), in their study on the psychological impact of physical

distance, also points out the loss of routine as an important stressor, suggesting the need to create specific support and communication networks to minimize these problems.

In this rupture process, the issue of overlapping tasks for the family caregiver is an important issue to be followed up. People who need to carry out the care activity at home are not limited to these tasks only. Most caregivers deal with their families with cognitive impairments, as in the case of dementias, which require full-time care, including maintaining health and supplementary care, for example, cleaning food and clothing, caring for the hygiene of hands, wearing and caring for the mask, during the COVID-19 pandemic period (Chan et al., 2020). Also, they need to carry out other activities that make up the routine of these caregivers, such as caring for other dependent people, carrying out work, and caring for the home, family, and oneself without being able to receive help from family members who until then collaborated with care, which generated an even greater burden. A caregiver showed difficulty in carrying out the care activities alone during this period:

My daughter [...] works all day, she doesn't care. But my son helps a lot, but with the pandemic, he rented a house in the countryside. They usually take us, but now I can't take my husband with me anymore! Now they go there and I stay here. (C1, wife, 75 years old).

A caregiver complained about the inclusion of new activities and care required and necessary during the COVID-19 pandemic period, which had an impact on overlapping tasks:

Today was the fair day so can you imagine? All the preparation to leave, all the preparation to enter, then you have to wash everything, clean everything. And I bought chicken, I have to clean it to freeze it, I washed clothes... a lot of things. (C3, husband, 70 years old).

Chan et al. (2020) identified that family caregivers did not have adequate knowledge and information about health care duties, which increased psychological stress. In this research, it was evident the lack of experience and training for adequate care of the elderly at home, in which, often, the environmental context is not considered, and also the lack of equipment and materials necessary to provide care.

The following report shows how the issue of task overlap came up during the period of physical distance:

I had to dismiss the girl who helped here at home, so it is difficult because I have to take care of the house, I cook, and my mother, she is fine, she does things, she helps, but there are things she ends up forgetting. With this quarantine, she was used to taking a walk here in Rebouças every day and now she is not able to leave the house [...] it is difficult because my mother is still with many habits and now with quarantine ended up accentuating more. (C4, daughter, 47 years old).

Older people are more vulnerable to natural disasters and crises, especially those who have some type of impairment, as in the case of dementias. In the context of the COVID-19 pandemic, older people with cognitive impairment have a greater chance of contamination because they do not remember to follow the guidelines recommended by the World Health Organization. Older people with these conditions have greater difficulties in adhering to new care strategies, such as wearing masks, wash their hands frequently, use gel alcohol and understand public health recommendations (Huali et al., 2020; Koutogelos et al., 2020).

Our group identified in the speeches of these caregivers that the forgetfulness common to dementia has become a daily challenge in their care activities.

The post office [arrived], I had to go and get it because if she picks it up, she doesn't wash her hand, she doesn't use alcohol. So, I go and then I take care because leaving is the same thing as nothing. So, when I know that, I push it away as much as possible. For example, I put a padlock in the mailbox so that it wouldn't pick up anything. Then I go there and get it. So, I am trying to do everything to have minimum contact with outside. Sometimes I go out, sometimes we just go out together so she can go to the doctor or do tests, that's all. The rest she stays at home, I go out because she puts her hand everywhere, she is not aware of the danger that we are experiencing. (C3, husband, 70 years old).

Ensuring the health of family members with dementia becomes a stressful factor in the care routine. The fear of their contamination and the other is an overload factor in the mental health of these family caregivers. Brooks et al. (2020) on the psychological impact of physical distance reported that caregivers fear their health and fear of infecting other people. The concern was related to the perception and observation of some common physical symptoms in the disease that could contaminate their family members. The following statement corroborates the findings.

I already come home worried, because I have to wash things, I take a shower, I take off my mask. Then I wash things all right so they don't have to pick up something and without risk of becoming infected. I'm already tense, you know?! Going out and end up going through something. Like last Sunday I went to the emergency room. Thank God there was no one! I took him to APAS and it was quiet, but I was already worried, looking all the time, passing alcohol gel, I put on 2 masks. (C4, daughter, 47 years old).

The COVID-19 pandemic has imposed a series of restrictions and new social configurations, in which the family of these older people has a fundamental role in supporting actions and in improving their quality of life, aiming to reduce their impacts (Camacho et al., 2020). Jiménez et al. (2019) pointed out that taking care of a person with dementia in times of physical distancing has brought more challenges than for the population in general, given the need to seek guidance on what and how to do to implement cognitive and functional stimulation activities, access the social networks to minimize social distancing, conduct teleconsultations, search for support, participate in

other significant tasks appropriate to the virtual format, among others. This context brought the need to readjust this daily life, as pointed out by the caregiver below.

It's a little difficult because since the quarantine started, she lost the routine she had. She went to the gym with my grandfather, she always went out every day, she went to visit my aunt, so since the year. In the past, she had a whole routine that was broken. So, I feel that since the pandemic started, her dementia has taken off a little. (C5, granddaughter, 20 years old).

A caregiver son developed stimulation activities with his mother through painting drawings, collage, writing, reading, and music activities. He referred to inserting her birthday planning to encourage participation in the cognitive stimulation process that involved everything from the choice of decoration and menu to the guest list.

I said "mom, who are we going to call? Let's make an invitation card, let's elaborate and start with the family members" and she started to list those people. [...] "Now what neighbors are we going to call?" and she said "Ah, we're going to call that one [...]" and I asked "What's his name?". Some things I saw that she had difficulties with, then I helped. (C6, son, 49 years old).

Another son reported the need to include activities in his father's daily life during physical distancing:

There was a problem with my mother's phone. I changed the plugs and he [my father] helped me. He kept looking for the tools with the wrench. So that took almost 2 days there all afternoon. So I also try to involve him in some things that do not create a risk for him, but I usually put him to feel useful and he does well, it helps a lot. (C8, son, 51 years old).

3rd - Behavioral changes and their relationship with the caregiver's mental health

The behavioral and psychological symptoms of dementia (SCPD) commonly associated with dementias are markers of greater burden and stress for the caregiver and increase both the prevalence of early institutionalization of the older person and the higher level of physical and psychological violence (Caramelli & Bottino, 2007; Júnior & Souza, 2017). Among the main SCPD are depression, apathy, hallucinations, delusions, agitation, sleep disorders, eating disorders, disinhibition, and aberrant motor behavior, in which their frequency tends to increase with the progression of dementia (Selbaek et al., 2007; Lyketsos et al., 2011).

With physical distancing and a sudden change in routine, the older person with dementia who already have SCPD shows these marked behaviors. It may also be common for those who have not manifested SCPD to start exhibiting such behaviors. These symptoms directly and negatively influence the physical and social environment and affect the quality of care, as they increase the caregiver's stress (Allegrì et al., 2006; Cuffaro et al., 2020; Kontoagelos et al., 2020). The appearance or exacerbation of these

symptoms during physical distancing was common in some of the statements of caregivers:

Actually, the tasks are not tiring, what stresses me the most is the constant repetition of the same questions and the “tidying up” of the things she does because she messes up the things I had done (laughs). (C3, husband, 70 years old).

The worst period is at night; we sleep in the same room. This year she is having many episodes of agitation and we spent many nights without sleep or bad sleep, I can hardly sleep during the day. (C7, daughter, 63 years old).

C4 (daughter, 47 years old) showed that her father's behavioral symptoms were exacerbated with physical distancing.

At 5 p.m. the confusion begins. He no longer wants to take the medicine and asks to go home. When we watch television and the 6:00 pm soap opera begins, we have to change the channel, because he thinks the soap opera is at home, that the characters are here. So, this schedule is very complicated. Today he is very confused because he wants to leave. I say that he can't leave because of COVID. (C4, daughter, 47 years old).

With the manifestation of these symptoms, the demands for guidance on the management of these SPCDs increased. The group brought the possibility of guidance, information, and discussion about why such changes were accentuated in the distancing period and collaborated so that the caregivers could implement practical management strategies and minimize stress and overload. Our participants shared about the positive effects of these guidelines and said they felt better oriented to try to deal with situations more lightly.

But what this exercise ended up helping a lot for me was that I also ended up exercising my patience [...] I started to realize that I could have more patience with the things [...] gave a good improvement. It gave us a better tuning. (C3, husband, 70 years old):

This week, through another meeting we had, I tried to put more into action the situation of getting out of the moment of conflict, taking a deep breath, and trying to get back to the situation again. Today I did it. (C6, son, 49 years old).

Reports like these show the importance of these virtual spaces as a support network, both for guidance and for welcoming and listening to these caregivers who experience many stressful situations during their daily lives.

4th - The support network as a health marker

Changes in routine such as those experienced today, require a capacity for resilience to adapt to the new reality since they remain for long periods and they expose individuals to greater risks of developing depressive and anxiety symptoms (Armitage & Nellums,

2020; Kontoagelos et al., 2020). Therefore, support for mental health was defined as an essential service during this period (D'Agostino et al., 2020).

The pandemic led to an unprecedented dependence on home care, resulting in new challenges during the care process. As a consequence of the change in lifestyle and restrictions, we have the feeling of loneliness (Holmes et al., 2020). This reality encourages us to reflect on the particularities and difficulties faced by caregivers during this period. It was evident in the reports that participation in the support group was for some of them the only possibility to minimize the feeling of loneliness.

In fact, even if it's not isolation, it's just the two of us, we don't have children [...] so there are no great conversations, [...] and I have no one to talk to. (C3, husband, 70 years old).

During the pandemic, those caregivers who were able to count on a wide social support network, such as the relay between family members and/or the presence of a professional caregiver, for example, did not report feeling the need to participate in the group to minimize the feeling of loneliness. However, most of the group participants had an impoverishment of their support network, being the group an important resource to minimize the psychological impacts of the restriction of the support network, accentuated by the distance in the caregiver.

My daughter works at home now, she works all day, she doesn't care. My son helps a lot, But with the pandemic, they rented a house in the countryside [...], they usually take us, but now it is no longer possible to take my husband along! Now they go there and I stay here. (C1, wife, 75 years old).

In this scenario, the use of technologies to create virtual environments has shown positive effects, especially for those families and/or caregivers with limited or impoverished social support networks to collaborate to improve the well-being of these caregivers, which was corroborated in our research (D'Agostino et al., 2020).

These meetings bring us encouragement, they work like a big warm hug. (C2, wife, 68 years old).

These meetings have helped me a lot! Gratitude!. (C4, daughter, 47 years old).

And this question of us exchanging stickers is very interesting because it is often a situation that the other is experiencing and that he is suddenly mirroring in what you are experiencing. (C6, son, 49 years old).

Social contact, even if virtual, minimized the symptoms of depression, anxiety, and the feeling of loneliness, favoring the feeling of belonging and allowed space for exchanging experiences and welcoming (Chan et al., 2020).

5th - New way to carry out meaningful activities

It is extremely healthy and recommended that both people with dementia and their family caregivers keep their activities meaningful and pleasurable such as physical, social, and/or leisure, among others. For this to happen, that caregivers should receive guidelines that can be applied strategically and with adequate resources, according to the level of cognitive and functional impairment of each family member with dementia, the previous history of activities and interests in the period of pre-pandemic of COVID-19. Many of these caregivers were unable to adapt their family members' previous activities to be carried out at home or use technological resources.

C4 (daughter, 47 years old), who takes care of the father with Parkinson's disease and normal pressure hydrocephalus and the mother with dementia, mentioned offering the same activity to both and noted that both did not respond in the same way, which led her to do not offer more activities to the father.

C4 (daughter, 47 years old) "The exercises, my mother managed to do [...] and my father did not. I explained, she explained and he didn't. He took the paper sheet, turned it over. So the exercise works with her, with him did not..."

The group provided access to information on how to graduate cognitive, manual, and/or artisanal stimulation activities, according to each case, encouraged the exchange and sharing of cultural and leisure activities, and fed participants the desire to explore other ways of doing. To this end, they used messages through WhatsApp, meetings through Zoom to carry out virtual tours to museums and parks around the world.

For caregivers, the impact of physical distancing is even more critical, as they are faced with a new universe of diverse and daily responsibilities arising from the process of caring for dementia with the aggravation of the pandemic (Holmes et al., 2020; Schapira et al., 2020). In this context, it became common to hear the expression "the new normal" as the possibility to readjust the daily routine and guarantee the performance of work activities, physical, social, and cultural activities during daily life in the virtual format to maintain physical balance and emotional. For the caregiver who lives in the same residence as his relative with dementia, this reality does not reach the minimum necessary for the balance of mind and body. Many of them referred to the intrusion or the crossing of their significant activities by their family members.

The balance is very complicated because when I stop to try to address something for myself, I am almost always interrupted. (C6, son, 49 years old).

For those who provide assistance and care at a distance or take care, it is possible to experience and apply "**the new normal**" in their daily routine. The caregiver daughter who lives with her mother, but who receives the help of a professional caregiver reports:

I manage to do my pleasurable activities [...] I take care of the plants, watch a movie, walk with my dogs during the day and play on the internet. (C10, daughter, 61 years old).

We observed that social, economic, and demographic issues are inextricably linked to the quality of life and self-care of caregivers. This is because those who have better financial resources can compensate for the absence of an effective support network. However, even those with a larger family network do not have the possibility of dividing tasks and caring for their parents, or spouses, being overburdened. Thus, it is essential to develop public policies aimed at people with dementia and their caregivers so that they can have their rights guaranteed by the state, especially when they do not receive family support.

Final Considerations

During the meetings, we observed problems such as the lack of information in the marked cognitive and behavioral changes in the relative with dementia, little or no psychological support in the face of overlapping demands, fear of contamination of themselves and others, restrictions in the home space for reconciling work activities and home demands were frequent reports by family caregivers. Such demands, in an environment in which it is not possible to count on their usual support network (relatives, neighbors/friends, employees of the home), led the caregiver to the manifestation of psychological compromises, such as fear, insecurity, guilt, anger, among others.

The experience of virtual support proved to be a powerful resource that can be used as a tool for accessing information and guidance for dementia and about caring for family members with dementia, based on cognitive and behavioral changes accentuated with physical distancing. The constant exchanges of common experiences in caregivers strengthened the bonds between them and were legitimized as a space for safe and empathetic listening and welcoming.

However, the limited number of participants can limit discussions and possibilities of generalization to caregivers who live in different contexts such as social, economic, intellectual, cultural, and access and use of technological resources.

Through the virtual support group for family caregivers, we could create technological possibilities and strategies that addressed the needs of this group, with specific guidance actions, such as techniques to simplify communication with the person with dementia, and more complex guidelines, when there is the need for guidance on how to manage behavioral and psychological changes in dementia, and actions aimed at the caregiver's self-care with an impact on their emotional state and well-being, minimizing the feeling of social isolation during the COVID-19 pandemic.

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Emanuela Bezerra Torres Mattos: Conception of the text, analysis of the collected material, writing of the text, and final review. Isabela da Costa Francisco: Conception of the text, Writing of the text, and final review. Gabrielle Christine Pereira: Conception of the text, Writing of the text, and final review. Marcia Maria Pires Camargo Novelli: Writing of the text and final review. All authors approved the final version of the article.

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Corresponding author

Emanuela Bezerra Torres Mattos

E-mail: emattos@unifesp.br

Section editor

Prof. Dr. Iza Faria-Fortini