

Caregiver Tele-Assistance for Reduction of Emotional Distress During the COVID-19 Pandemic. Psychological Support to Caregivers of People with Dementia: The Italian Experience

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Abstract.

Background: COVID-19 pandemic worsened vulnerability of patients with dementia (PWD). This new reality associated with government restriction and isolation worsened stress burden and psychological frailties in PWD caregivers.

Objective: To give tele-psychological support to caregivers and evaluate the effect of this intervention by quantifying stress burden and quality of life during the first COVID-19 lockdown.

Methods: 50 caregivers were divided into two groups: “Caregiver-focused group” (Cg) and “Patient-focused group” (Pg). Both groups received telephone contact every 2 weeks over a 28-week period, but the content of the call was different: in Cg, caregivers answered questions about the state of the PWD but also explored their own emotional state, stress burden, and quality of life. In Pg instead, telephone contacts were focused only on the PWD, and no evaluation regarding the caregiver mood or state of stress was made. Psychometric scales were administered to evaluate COVID-19 impact, stress burden, and quality of life.

Results: Considering the time of intervention, from baseline (W0) to W28, Zarit Burden Interview and Quality of Life-caregiver questionnaires remained unchanged in Cg as compared with baseline ($p > 0.05$), whereas they worsened significantly in Pg ($p < 0.01$), showing increased stress over time and decreased quality of life in this group. Moreover, Impact on Event Scale values improved over the weeks in Cg ($p = 0.015$), while they remained unchanged in Pg ($p = 0.483$).

Conclusion: Caregivers who received telephone support about their mood and stress burden did not worsen their psychological state during the time of intervention, as did instead those who did not get such support.

Keywords: Caregiver, COVID-19 pandemic, people with dementia, quality of life, stress burden, tele-psychological support

INTRODUCTION

Currently, more than 50 million people have dementia worldwide [1]. Dementia is associated with varying degrees of cognitive decline and behavioral changes, which have a huge impact on the quality

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of life of persons affected and their relatives. During normal times, people with dementia (PWD) are very vulnerable and dependent on family or professional caregivers in everyday life.

The 2019 new coronavirus disease (COVID-19) was declared a “Public Health Emergency of International Concern” (PHIC) on January 30, 2020, and the World Health Organization (WHO) declared the “COVID-19 pandemic” on March 11, 2020 [2].

This COVID-19 pandemic worsened vulnerability of PWD directly: a diagnosis of dementia is in fact an important risk factor for mortality in patients with COVID-19 [3]. Many countries have implemented strict public health measures to protect vulnerable groups such as PWD from the deleterious physical effects of COVID-19. In Italy, the first strict lockdown lasted almost 3 months (March-May 2020) with severe restrictions in daily living habits.

Psychological changes become evident after the introduction of the restrictions applied by the Government during the COVID-19 pandemic, such as social distancing and limitations in individual mobility and social activities. These restrictions may have had negative consequences on the possibility of being psychologically and emotively supported by others; low social support has been associated with higher depression in caregivers [4].

During this period, caregivers might have experienced higher than usual stress and burden because communication and coordination with healthcare providers was difficult, thus they were unable to rely on their usual network of formal and informal in-home supports, face escalating challenges in accessing needed in-home care. Additionally, support programs, such as adult day health care, may not be available. Caregivers may also experience negative physical and mental health outcomes. Many caregivers experienced feelings of social isolation, which may be exacerbated by social distancing policy measures. Older caregivers may be at particular risk for injury as they take on additional hands-on caregiving responsibilities, such as assisting with mobility and transfers in the absence of other help. Added caregiver burden and lack of informal care prevented older care recipients from being safely maintained in their homes, increasing the risk for requiring care in emergency departments, hospitals, or long-term care facilities [5].

In this new reality, caregivers often experienced high burden that negatively compromised their mental wellbeing, as a result of the loneliness brought about by the confinement and isolation. This has been

associated with health problems such as compassion fatigue that force some family caregivers to relinquish care roles of their loved ones to long-term care [6, 7].

Isolation had negative effects in about half of PWD, also for the discontinuation of essential services for their care [8, 9]. Prolonged time of isolation had negative effects on caregivers, as demonstrated by higher levels of depression and anxiety [10]. Educational level appears to be a protective factor. Women seem to suffer the consequences of the lockdown on anxiety, depression, and stress more than the men [11].

Quarantine induced a rapid increase of behavioral and psychological symptoms of dementia (BPSD) in approximately 60% of patients and stress-related symptoms in two-thirds of caregivers. An increased prevalence of symptoms of anxiety, feeling of helplessness, and anguish were reported by caregivers [8]. Increased concerns for patient health and increased familial conflicts were also reported [8]. Presence of housemates reduced the risk of depression and conflicts, thus indicating that caregiver burden may be mitigated by contrasting loneliness and supporting needs of caring with a network of helps. There seems to be an association between psychological symptoms of anxiety and depression in caregivers and increased BPSD burden [8–12].

The COVID-19 pandemic is unmasking an emerging form of technology-related social inequalities that become a major factor of vulnerability. A series of political and community interventions aiming to solidify the social safety net is needed to support the most socially vulnerable population and prevent increasing both their vulnerability to the pandemic and the social health inequalities [13, 14].

Considering all the above, the aim of this study was to: 1) give tele-psychological support to caregivers and evaluate the effect of this intervention by quantifying stress burden and quality of life during COVID-19 lockdown period (from April to November 2020), 2) evaluate psychological impact of COVID-19 pandemic in caregivers of PWD.

METHODS

Participants

Caregivers were recruited through local database collected in Neurodegenerative Disease Unit of the Fondazione IRCCS Ca' Granda Ospedale Maggiore Policlinico, Milan. Recruitment has been carried out from April to May 2020 and involved caregivers of PWD. Patients and their caregivers have had a follow

up visit at our outpatient service over the last year before the pandemic. The study was approved by the Local Ethics Committee ('Milano - Area 2', number 362_2020 - April 30th, 2020).

Participants' inclusion criteria were: A) be PWD caregiver, cohabitant or not, B) give oral informed consent, C) age > 18 years, D) understand and communicate in Italian language, E) be able to understand and answer the questions, F) spend 8 hours or more per week with PWD (before COVID-19 pandemic lockdown).

One hundred and nine caregivers were contacted by phone, and 50 of them fulfilled inclusion criteria and accepted to participate.

All participants had a first telephone contact with a psychologist. At baseline (Week 0 – W0) the following tests were administered:

- COVID-19 questionnaire: a new questionnaire was created to explore caregiver changes during national lockdown for COVID-19 infection. The questionnaire included: 1) sociodemographic information about caregiver who completed (i.e., town, age, job), 2) clinical information about relatives PWD (i.e., relationship, diagnosis, type and level of disease), 3) daily habits related with PWD (i.e., weekly hours spent together, help in care management, free time, emotional state, mood, communication skills). Issues included in point 3) were analyzed before (using retrospective questions) and during COVID-19 lockdown. Notably, the questionnaire has not been developed as a quantitative scale to be validated but as an instrument to get relevant information over a phone call duration.
- Neuropsychiatric Inventory (NPI) [15]
- Zarit Burden Interview (ZBI) [16]
- Quality Of Life caregiver (QOL- cg) [17]
- Impact of Event Scale – revised (IES) [18].

After this first step, participants were randomly divided into two groups: "Caregiver-focused group" (Cg: psychological telephone contacts with interview about PWD, exploring also emotional state, stress burden, and quality of life of caregiver) and "Patient-focused group" (Pg: psychological telephone contacts with interview about PWD, no evaluation about caregiver mood or state of stress). Randomization was performed using the random function of Microsoft Excel. Diagnoses at inclusion were as follows: 26 patients had Alzheimer's disease (Cg/Pg: 11/15), 4 frontotemporal dementia (Cg/Pg:

2/2), 6 Lewy body dementia (Cg/Pg: 3/3), 3 primary progressive aphasia (Cg/Pg: 2/1), 9 other dementias (vascular dementia or mixed dementia; Cg/Pg: 5/4). There were no significant differences in terms of frequency of diagnoses between Cg and Pg.

Telephone contacts (15 min) were made every two weeks over a 28-week period (from April to November 2020) by trained clinical psychologists. Assessment at Week 28 (W28) were done using: ZBI, QOL-cg, IES, and questionnaire about telephone contact satisfaction and usefulness.

At 32 weeks (Week 32- W32) (within December 2020) a further follow up was done including ZBI and QOL-cg (Fig. 1).

Statistical analysis

The data obtained from the study were analyzed using statistical analysis software Jamovi (<https://www.jamovi.org/>). Frequency and percentage were used for categorical data, whereas mean and standard deviation values were used for continuous data. Chi-square test was used for the analysis of categorical data, and t student and repeated measures ANOVA were used in the analysis of continuous data. Values with $p < 0.05$ were considered statistically significant.

RESULTS

Fifty participants were randomly assigned into two groups: 25 in Cg and 25 in Pg. After the random distribution, 2 caregivers in Cg refused to continue, therefore a total of 48 participants (33 women, 15 men) agreed to participate in the study: 23 were in Cg and 25 in Pg.

Demographics and details of the population are reported in Tables 1 and 2. No significant differences in age, sex distribution, and schooling were found between participants' groups. Regarding the cognitive state of PWD, mean value of Mini-Mental State Examination (MMSE) [19] in patients followed by Cg caregivers was 17.4, whereas in PWD followed by caregivers of the Pg group was 18.4 ($p > 0.05$). Time from diagnosis, age, and schooling of PWD were also not statistically different ($p > 0.05$).

Thirteen out of 48 caregivers dropped out during the study (6/23 in Cg and 7/25 in Pg, $p = 0.882$). Reasons were multiple: personal problems (work or smart-working for 8/10 hour a day, major changes in family routine, hospitalization for illness) and troubles about patients (aid reduction in patient care and assistance, inside and outside home). In none of the

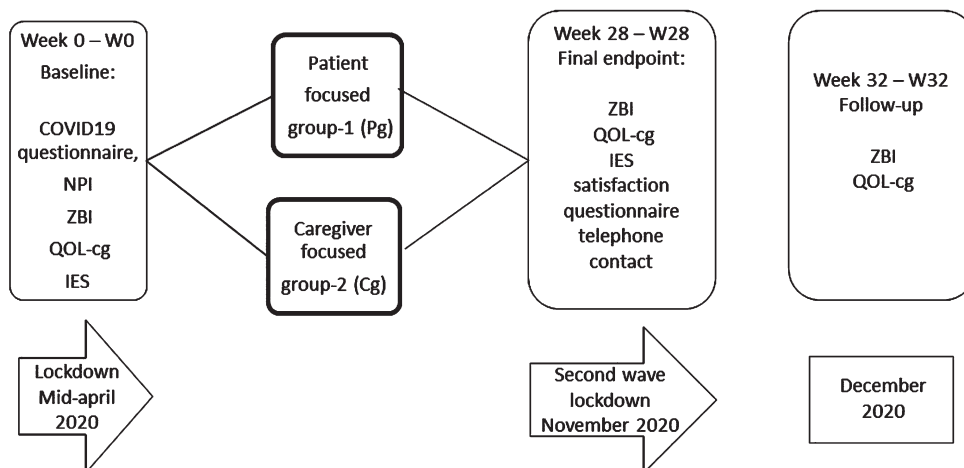


Fig. 1. Study timeline and pandemic situation in Italy.

Table 1
Demographic characteristics of participants and comparison between the two groups
(Cg versus Pg) using *t*-test analysis and Chi-square test

	Cg (23)	Pg (25)	p
Age (y, mean \pm SD)	67.8 \pm 12.79	61.2 \pm 18.47	0.195
Education (y, mean \pm SD)	12.2 \pm 3.99	12.9 \pm 4.99	0.616
Gender (M:F)	7:16	10:15	0.489

SD, standard deviation.

Table 2
Characteristics of PWD and comparison between the two groups (Cg versus Pg) using
t-test analysis and Chi-square test

		Cg (23)	Pg (25)	p
Mini-Mental State Examination (mean \pm SD)		18.4 \pm 7.21	17.4 \pm 6.58	0.606
Years of disease	1–3	6	6	0.868
	4–6	10	11	0.971
	7–10	4	5	0.817
	>10	3	3	0.913
Diagnosis	AD	11	15	0.398
	FTD	2	2	0.931
	LBD	3	3	0.913
	PPA	2	4	0.502
	Other	5	4	0.611
Patient Impairment	Cognitive	23	25	1.00
	Anosognosia	10	6	0.153
	Impact in daily living	18	15	0.173
Level of cognitive impairment	Behavioral	14	14	0.732
	Mild	9	8	0.606
	Moderate	7	11	0.332
	Severe	7	5	0.404
	Bedridden	0	1	0.332

SD, standard deviation.

cases was the drop out due to COVID development in patients or caregivers.

To evaluate the evolution of stress burden (using ZBI) and quality of life (using QOL-cg), we compared questionnaire values at timepoints W0 and W28 (intervention) and follow-up W28-W32 (no

intervention) in each group using repeated measures ANOVA. To evaluate pandemic impact, we compared IES questionnaire at timepoints W0 and W28 using repeated measures ANOVA.

Considering the time of intervention, from baseline (W0) to W28, ZBI and QOL-cg questionnaires

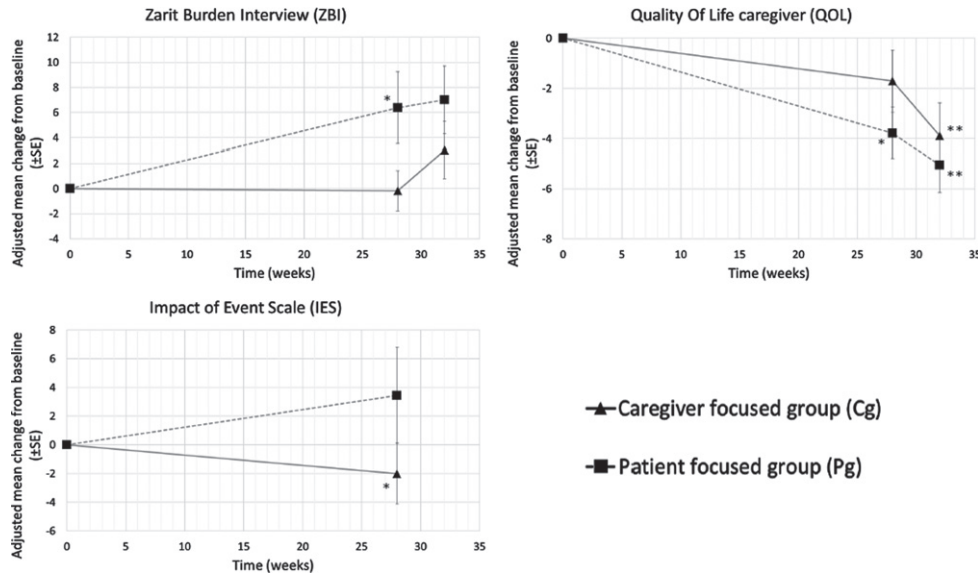


Fig. 2. ZBI, QOL-cg, and IES questionnaires adjusted mean change from baseline in Pg and Cg at timepoints W0-W28-W32 (initial values of patient were subtracted from each value before obtaining the mean). IES questionnaire comparison between Pg and Cg groups at timepoints W0-W28 using repeated measures ANOVA. p values refer to comparisons in the same group over time. * p values: W28 versus baseline; ** p values: W32 versus W28.

remained unchanged in Cg as compared with baseline (ZBI: $p = 1$, QOL-cg: $p = 0.108$), whereas worsened significantly in Pg ($p = 0.017$ and $p < 0.001$, respectively, Fig. 2), showing increased stress over time and decreased quality of life in this group. Moreover, IES values improved over the weeks ($p = 0.015$) in Cg, while remained unchanged in Pg ($p = 0.483$, Fig. 2).

At follow up (W32–no intervention–as compared with W28), ZBI and QoL worsened in both groups, with a marked increase of ZBI in Cg (Fig. 2), although the statistical threshold was not reached. Instead, QoL was significantly changed ($p = 0.029$ in Cg and $p = 0.025$ in Pg, Fig. 2).

All caregivers (Pg and Cg) who were available to complete the study (32 weeks) appreciated this psychological telephone contacts and the opportunity to speak directly with a psychologist [35/35]. In Cg, satisfaction was 8.9/10 and in Pg 8.4/10 ($p = 0.134$). Regarding psychological telephone contacts content, Cg give a higher satisfaction score (8.5/10, about COVID-19 7.76/10) than Pg (7.1/10, $p < 0.001$ and about COVID-19 6.2/10, $p < 0.05$).

DISCUSSION

The present study aimed, firstly, at investigating levels of stress burden and quality of life in caregivers of PWD during the 2020 lockdown due to the COVID-19 pandemic and support them through psy-

chological telephone contacts (telephonic counseling sessions every two weeks) and secondly to evaluate the psychological impact of COVID-19 pandemic in caregivers of PWD.

We showed that caregivers who received psychological telephone support about their mood and stress burden (Cg) did not worsen over time from the beginning of restrictions, and gave the same values at questionnaires. Conversely, caregivers contacted just to ask the health conditions of PWD (Pg) worsened. Therefore, psychological telephone intervention is an important instrument to support caregiver in stress management and perception of their quality of life. The ability to express their mood, be heard, and feel understood could be very helpful for people that every day spend time, energy, and emotion with PWD. Therefore, we hypothesize that introducing a direct communication through psychological telephone contacts and engaging caregivers about their distress would be beneficial, not only in caregivers of PWD but possibly also in those of other irreversible conditions. This approach, easy and cheap, could be included in clinical settings of Neurodegenerative Disease Units, or in general in all Clinical Hospital Units. Notably, the severity of dementia of patients followed by caregivers in both groups was similar, thus avoiding any bias due to the cognitive state of PWD. However, no details were available on different (behavioral or not) aspects, which could

influence caregivers' stress burden, such as aggressiveness, impulsiveness, hypersexuality, or insomnia.

Of notice, at follow up, QoL worsened in both groups as compared with the end of the intervention, suggesting that any kind of support may have a beneficial effect on caregivers. Nevertheless, the most striking change was observed in ZBI in Cg, that was unchanged over the time of intervention and increased suddenly right after the end on the study, suggesting a detrimental effect in Cg after stopping the psychological support.

We acknowledge that the follow up has been done for four weeks only, thus no definitive results can be ruled out. However, the trend of abrupt worsening in Cg suggests that, in view of a longer beneficial effect, the intervention should be continuative over time, possibly with different timing (i.e., every four weeks instead of two) for a matter of feasibility in terms of time and costs.

The COVID-19 pandemic has forced dramatic changes in medical and psychological care delivery. Safety concerns regarding viral transmission have led to restrictions in face-to-face clinical encounters and increased use of telehealth approaches [20, 21]. Alzheimer Europe recommends the following for PWD and their caregivers: building a support network, keeping well informed, guaranteeing food and medical supplies, enjoying leisure activities, staying physically and mentally active, and keeping socially connected [22]. In the age of information and communications technology, technology home-based interventions [23] (smartphones, tablets, computers, smart televisions, virtual assistants, ambient assistive devices, etc.) can support most of the above recommendations; they facilitate information sharing and online shopping, provide access to entertainment, increase social connectiveness, and, most importantly, these interventions enable the distribution of health-related information and services. Telehealth is a potential major tool to deliver routine health care and prevent the risk of viral exposure, especially for people at higher risk [24, 25]. Numerous studies conducted in the recent years have reported that informal/family dementia caregivers can access Internet-based interventions, and they received positive effects on their wellbeing [28–32]. The COVID-19 pandemic is unmasking an emerging form of technology-related social inequalities: political and community interventions are needed to support the most socially vulnerable population and prevent social health inequalities. We choose a direct communication using telephone, bypassing caregiver

inability to use tablet or PC and internet connection difficulties [13]. Our results underline the need of caregivers to be supported in the patient care, particularly in critical situations related to COVID-19 pandemic.

Given the opportunity to speak and be heard directly by a health worker (in this case a psychologist) makes the caregivers feel closer and supported by the health facilities. Thus, if the content of this contact is supportive from a psychological point of view (talking about stress, emotional state), it improves subjective satisfaction and gives the caregiver support to control the load of stress and improve the quality of life (as shown by changes in ZBI and QOL-cg, respectively). Similarly, the adaptability to the impact of the pandemic situation in daily life during lockdown months resulted higher; the Cg group seems to be better adapted to the impact of the pandemic situation in daily life during lockdown months. Otherwise, in Pg, stress burden increased and quality of life got worse, although the COVID-19 pandemic impact did not apparently change over the period of study.

We are aware that the COVID-19 pandemic is a component out of our control, and it might have affected the caregiver answers to the questionnaires. On the other hand, based on our data, the lockdown impact was not the main worry of caregivers, although it was a variable that worsened an already existing frail situation. For this reason, independent of the COVID, we hypothesize that the opportunity to have a psychological telephone contacts could be beneficial to all caregivers, i.e., not only in this emergency, but also in clinical routine. Stress burden and quality of life remained unchanged despite the pandemic situation in caregivers who received the telephone support (focused on patient and own psychological situation). In line with this, data published in the pre-COVID era suggest that interventions delivered via telephone and computer have the potential to augment existing dementia care, particularly those that provide caregivers with access to practical strategies to manage care of PWD and their own wellbeing, advice and support from peers and/or clinicians [33].

In conclusion, in our study we followed a group of caregivers for 32 weeks (28 weeks of treatment and 4 weeks of follow-up), a long period in a critical period of COVID-19 pandemic, and gave them substantial support. We tested psychological intervention using telephone contact and demonstrated it to be very useful to overcome the restrictions. We think our results underline the importance of telepsychological support, but further studies in larger

cohorts would be needed to confirm our preliminary data. Unfortunately, in this study the average of drop out was high. Nevertheless, this would be hard to avoid in a population with a considerable burden of activity, linked to its own life and PWD care out of our control. In addition, it cannot be excluded that the sample participating in the study was not biased by other variables (number of family members, social condition, economic status. etc.), therefore confirmatory future studies on larger and better-defined populations would be needed.

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Authors' disclosures available online (<https://www.j-alz.com/manuscript-disclosures/21-5185r2>).

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