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The Impact of COVID-19 Restrictions on Caregivers of Individuals with Dementia

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Abstract

The COVID-19 pandemic has altered the structure of dementia centers to accommodate to public health guidelines. This study evaluates the psychological, social, and biological factors influencing caregivers of individuals with dementia as a result of the COVID-19 pandemic at a long-term dementia care facility in Texas. Between January 15, 2021 and April 15, 2021, 38 caregivers participated in an anonymous electronic survey. The mean total burnout score was 36.43 out of 70. 73.68% reported a decreased connection with their loved ones. 59.46% believe that their loved ones have had more cognitive decline as a result of the COVID-19 pandemic. Our findings suggest that caregivers have faced several deleterious effects as a result of the restrictions imposed by the pandemic, which has led to increased feelings of burnout among caregivers.

Introduction

The COVID-19 pandemic has completely altered social constructs and communication methods. The emphasis on social distancing has changed the norms around interacting with others. This pandemic has drastically changed everyone's lifestyles, and it has had unintended consequences on individuals with dementia. The dementia population has already been considered vulnerable before the pandemic, and the outbreak has further worsened their vulnerability because of the direct effects of COVID-19 on morbidity and mortality in addition to the indirect effects caused by a disruption in social support. Individuals with dementia heavily rely on chronicity of care, which has been interrupted by the social shift caused by the pandemic. People with neurocognitive disorders rely on a standard daily routine, which helps control the behavioral and psychological symptoms of dementia among these individuals [1]. The dementia population has experienced worsening behavioral and psychological symptoms as a result of the decreased support and activities available to them. Individuals with dementia can also have problems understanding and retaining public health guidelines. As a result, people with dementia could have increased difficulty coping with safety measures that limit their social engagement. Moreover, COVID-19 deaths have disproportionately affected nursing homes. In order to limit the spread of the virus, the structure of dementia centers has been altered. The CDC guidelines for controlling COVID-19 in memory care units suggest that centers implement social distancing, face coverings, and frequent cleaning of surfaces. We focused our research specifically a dementia care center in Texas. To accommodate new public health safety guidelines, the center had initially prevented family members from entering the facility and interacting with loved ones undergoing care [2]. The organization has now allowed several families to visit with their loved ones through windows and even limited in-person visits in accordance with public health regulations in Tarrant County, Texas that dissuade against non-essential activities and in-person social gatherings. The center promotes caregiver education to support, train, and empower caregivers of individuals with dementia, and these sessions have been shifted to an online format to comply with social distancing policies that encourage limiting contact with others. Caregivers are normally susceptible to experiencing stress from taking care of their loved ones. The unprecedented shifts imposed by this pandemic has increased caregiver burden and exhausation, which puts caregivers at risk for experiencing burnout. There is scarce literature in regard to how caregivers view themselves in the context of a care team. In order to evaluate the sphere of influence impacting caregivers of individuals with dementia and their relationships with their loved ones since the COVID-19 outbreak, we structured our study around Georg L. Engel's Biopsychosocial Model, which embraces the interconnected nature of biological, psychological, and social factors (Engel, 1980). Biological factors include the COVID-19 diagnosis of caregivers and their loved ones as well as the physical activity level of caregivers. Sometimes when peoples' lives become more stressful, people have less opportunity to engage in physical activity. Because stress faced by caregivers has the potential to impact their activity, tracking biometrics such as steps taken and Heart Rate is important for a baseline assessment. Psychological factors consist of caregivers' personal fears and anxiety related to the care of their loved one in addition to their perceived confidence in the information they are receiving about their loved ones. Social factors include interactions of caregivers with their family, friends, and their loved ones. Social distancing has the potential to reduce social engagement and lead to isolation. Loneliness is a serious public health issue, particularly among the elderly, and it can lead to a cycle of illness.

Method

Following Institutional Review Board (IRB) approval, we performed a cross-sectional study utilizing a digital questionnaire from January 15, 2021 to April 15, 2021. Given the anonymous nature of the survey, an informal waiver of consent has been formally approved by the ethics committee. Our study population consisted of caregivers of individuals with dementia living at a care facility in Texas [3]. We conducted a review of existing surveys on this topic. A number of questions were identified and modified from Us Against Alzheimer's research series on the effect of COVID-19 restrictions on the Alzheimer's community, COVID-19 Pandemic Mental Health Questionnaire University of Miami's questionnaire on the well-being and health related quality of life of the cancer community to fit our population. We also designed some of our own questions. In order to assess the level of physical activity among caregivers, we asked participants to report their number of steps taken in a day and their Heart Rates. We included primarily multiple-choice questions with some narrative questions. We structured the answer choices of the multiple-choice questions to follow the Likert Scale. Five points were assigned to the option of Strongly Agree, 4 points to Agree, 3 points to Neither Agree nor Disagree, 2 points to Disagree, and 1 point to Strongly disagree. The survey consists of 18 questions with the option of answering 10 additional questions. The additional questions were completely optional. Both question sets ascertain biological factors, psychological factors, and social factors regarding caregivers' experience with COVID-19. The additional questions explore, provide depth, and add to the shorter questionnaire. However, the key probative questions are still addressed in the shorter version, and we have not lost anything by having a convenience questionnaire for timeliness. Responses were analyzed using Excel.

Results

Demographics

A total of 38 participants completed the survey. Thirty-seven participants completed the long questionnaire while only 1 participant completed the short questionnaire. Among them, 23 (60.53%) individuals had more than 5 years' experience serving as a caregiver, whereas only 2 (5.26%) of their loved ones have been living at the dementia care facility for more than 5 years (Table 1).

Demographic Variable	**Caregivers**	**Loved Ones**
Gender		
Female	0.8421	0.5263
Male	0.1579	0.4737
Age		
55-64 yrs	0.4474	0
65+ yrs	0.5526	1
Time Caregiving		
<6 months	0.0263	0.1053
6 months-1 year	0	0.1053
1 -3 years	0.1316	0.6053
3-5 years	0.2368	0.1316
>5 years	0.6053	0.0526

Table 1: Demographics of caregivers and loved ones.

Psychological and social factors

A high social engagement burnout score of 15-20 indicates limited interaction with others while a low score of 1-5 suggests the caregiver has been able to successfully maintain and foster interpersonal relationships. Out of a possible social engagement burnout score of 20, the mean total score was 10.92 (Table 2).

A decreased connection with their loved ones was noted in 73.68% of participants. Increased feelings of isolation and loneliness was documented in 14 caregivers [4]. An improvement in stress levels and engagement with friends and family members were noted in some cases. Of note, only 6 respondents reported an increase in the number of arguments with their family members over the last couple of weeks.

A high psychological burnout score of 40-50 indicates caregivers have fearful or uncertain thoughts about their loved one's condition and the pandemic while a low score of 10-20 suggests they have a positive attitude. Out of a possible psychological score of 50, the mean total score was 25.51.

An increase in stress over the last couple of weeks was described in 42.1% of the sample. 59.46% believe that their loved ones have had more cognitive decline as a result of the COVID-19 pandemic. Moreover, only 10 caregivers conveyed worry about their financial condition. A high burnout score of 60-70 signifies that caregivers have had trouble adjusting to the COVID-19 pandemic while a lower score of 10-25 suggests they adapted well. Out of a possible total burnout score of 70, the mean total score was 36.43.

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Variable	Minimum	Maximum	Mean	Std Dev
Social Engagement Score	6	16	10.92	2.84
Psychological Score	15	38	25.51	5.69
Total Score	22	51	36.43	7.62

Table 2: Burnout scores.

Biological factors

Out of the 19 respondents who reported the number of steps taken the day before completing the survey, the mean number of steps was 6143.05 (Table 3). This slightly less than the recommended approximately 8,000 steps among older adults (Tudor-Locke et al.,2020). Out of the 22 individuals who provided their heart rate the day they completed the survey, their average heart rate was 68.73. Among the 37 caregivers who provided their COVID-19 status, 83.3% of them reported they had tested negative during the outbreak. Of the 37 caregivers reporting their loved one's COVID-19 status, 69.4% of individuals indicated their loved one' had tested positive for COVID-19.

Variable	Minimum	Maximum	Mean	Std Dev
Number of Steps Taken	50	10612	6143.05	3069.73
Heart Rate	48	85	68.73	11.66

Table 3: Biological factors.

Narrative responses

Engagement with Loved Ones Respondents shared ways they have stayed in touch with their loved ones despite social distancing measures. Caregivers emphasized phone communication and visits. “For many months via FaceTime which does not work well anymore. I believe Mom has progressed to Stage 7 in the last year and Covid definitely made her worse” (Respondent 9) “Video calls placed by staff a few times each week. Since being allowed, I have visited once a week” (Respondent 10)“Facetime and window visit” (Respondent 26) “Facetime 4 times per week, essential caregiver visits with mask once per week” (Respondent 37) Managing the COVID-19 Pandemic. The lifestyle shift imposed by the outbreak has demanded individuals to find ways to adapt to and cope with the change. Caregivers reported that engagement with family members along with relaxing activities have been helpful.“Being grateful. Although my loved one's condition has definitely worsened since the pandemic began, I am incredibly grateful to be able to see and hold her” (Respondent 3)“Continuing to see my children and grandchildren, staying in touch with friends, needlepointing while watching TV, writing, and walking the dog” (Respondent 10)“Taking care of myself with oils and supplements” (Respondent 38) It is evident that some caregivers were committed to abiding by public health guidelines. “Social distancing and mask vaccines are the key to controlling this and most infectious disease epidemics” (Respondent 37) Wear mask and Wash hands.

Discussion

Our results indicate that the COVID-19 outbreak has impacted the attitudes and perceptions of caregivers in their care for their loved ones. Our findings suggest that caregivers have faced several deleterious effects as a result of the CDC guidelines put into place to limit the spread of the virus such as increased stress levels, feelings of loneliness, and worry of increased cognitive decline among their loved ones, which has led to increased feelings of burnout among caregivers. The World Health Organization announced COVID-19 as a pandemic on March 11, 2020 (World Health Organization, 2020). Our data was collected about 10 months into the pandemic, so the caregivers have been affected by this unprecedented change for a significant amount of time since the outbreak started. As a result, our findings provide insight into the more longer term effects the pandemic has had on caregivers of individuals with dementia. Along with the suggestions provided by the surveyed caregivers to maintain contact with their loved ones, Simulated Presence Therapy can also be used. This technique involves caregivers making audio recordings with evocative questions from past memories and with built in silence so that loved ones can respond to the questions and replay the recordings. We propose that caregivers combine other methods of communication such as phone calls, zoom encounters, or notes with Simulated Presence Therapy concurrently [5]. We also recommend regularly utilizing Stimulated Presence Therapy weekly. With this format, caregivers can ask questions about specific things in the recordings based on topics they recently discussed with their loved ones using other communication forms. For instance, caregivers can talk about their pet dog during a call with their loved ones on Tuesday, and caregivers can then ask about the dog again in a recording shared with their loved one on Saturday of the same week. This approach will allow individuals with dementia to specifically recall recent instances, and this continued reinforcement of recent memories will help them stay closely connected to their caregivers.

Conclusion

A strength of the study is the use of positive wording. Given that some of the questions could have reminded caregivers of some upsetting moments or situations with their loved ones, we ensured we selected questions and answer choices with a more uplifting tone to limit any potential distress. Additionally, we were cognizant of the potential stress caregivers may be facing in this COVID-19 world, so we did not want them to feel burdened by our survey. As a result, we provided the option of taking the short or long questionnaires to respect the choices and time of participants. A limitation to the study includes a gap in understanding of the actual physical activity level of respondents. The questionnaire was designed to allow individuals who did not use biometric applications on their phones to track their steps or measure their Heart Rate to still fill out the survey. As a result, there is gap in understanding these biometrics among all of our caregivers in our study. Moreover, the questionnaire did not account for individuals who had tested positive for COVID-19 multiple times during the pandemic. Because we only asked if caregivers or loved ones tested positive, it is possible individuals who contracted the virus multiple times were not appropriately accounted for given the data was collected at a single dementia center in an urban city, there was a limited study population. However, our partnership with a single institution allowed us to quickly and efficiently disseminate our questionnaire to the caregivers using their organizational database. Our findings may not be applicable to caregivers of individuals at dementia care institutions in more rural settings. Additional research is needed to understand the impacts of the outbreak on caregivers and their loved ones living in areas with more limited access to resources. Furthermore, we solely focused on caregivers with individuals living at a full-time dementia center, so research on caregivers of individuals living in other settings such as part-time dementia centers or fully at home with caregivers can provide insight into the unique needs of these populations. Nonetheless, our results help shed light into the common themes applicable to caregivers during the COVID-19 pandemic, which we believe can help inform the development and implementation of new public health policies and programming to better support this group.

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