

Review Article

Coping with Dementia Caregiving Stress and Burden during COVID-19

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Abstract

The coronavirus disease 2019 (COVID-19) pandemic presents unique challenges for vulnerable populations such as people with dementia and their caregivers. This article aims to raise awareness of increased stress and burden during shelter-in-place orders for caregivers and their loved ones, identify areas of interventions for coping, and generate discussion among practitioners and advocacy agencies to synergistically address the needs of these vulnerable populations. We propose a three-pronged approach including: 1) education about COVID-19 (i.e., risk and surges in locality) along with caregiver education about dementia, and future planning for emergencies; 2) behavioral management to proactively reduce or prevent increased stress in care recipients; and 3) engaging in self-compassion and care to fortify caregiver coping and reduce caregiver burden. We provide concrete examples for carrying these out throughout the article. Importantly, the concepts of dementia and caregiving vary significantly across cultures, and health practitioners are best able to assist families by gathering specific details about each family's caregiving situation, their knowledge about caregiving, and their access to resources. When providing referrals to resources, providers need to ensure that these are culturally specific for the individual and their families and accessible within their community.

Keywords: Caregiving; COVID-19; Dementia; Caregiver stress; Shelter-in-place

Abbreviations

SARS-CoV-2: Severe Acute Respiratory Syndrome Coronavirus-2; COVID-19: Coronavirus disease 2019; WHO: World Health Organization; CDC: Centers for Disease Control and Prevention; SIP: Shelter in Place; PWD: People/person with Dementia

Introduction

The World Health Organization (WHO) [1] declared the Severe Acute Respiratory Syndrome Coronavirus-2 (SARS-CoV-2) and the resulting condition, coronavirus disease 2019 (COVID-19) a pandemic on March 11, 2020. Many US states and localities issued workplace restrictions and "Shelter in Place" (SIP) or "Stay-at-home" orders to prevent the spread of the disease.

Pandemics have consequences on people's physical, financial and emotional wellbeing. Some of the emotional consequences of pandemics and the social isolation of quarantine include depression, anxiety, substance abuse, post-traumatic stress disorder, psychosis, and even suicidality [2,3]. The incidence of domestic violence also increases during SIP [4]. Moreover, shortages of supplies, inconsistent or insufficient information from government agencies, and misinformation from other sources, have added to the stress.

During the H1N1 pandemic, the Disaster Mental Health Subcommittee of the National Biodefense Science Board [5], recommended interventions to aid coping and resilience for the public, paying special attention to vulnerable populations. They defined vulnerable populations as the elderly, people with cognitive impairment, disabilities, underlying medical conditions, mental

health disorders, homeless, the poor, members of "diverse cultures"; people with limited English proficiency, and pregnant women. People With Dementia (PWD) are among the vulnerable populations. Older caregivers of PWD also fit the criteria for vulnerability. The current pandemic disproportionately impacts older adults [6], and furthermore, social conditions and structural racism have elevated risk of COVID-19 diagnosis and death in Black, Indigenous, and Latinx Americans [7,8]. Hence, PWD who are members of minoritized groups are at increased risk.

Our group has been working closely with elders with dementia and their caregivers both before and during the COVID-19 pandemic. The aim of this article is to raise awareness of the vulnerability of family dementia caregivers to increased stress and burden during COVID-19 and SIP orders. An additional goal is to identify areas of intervention for coping with stress, burden and isolation. Lastly, we hope this article will generate discussion among practitioners, advocacy agencies, and the public in synergistically addressing the special needs of dementia caregivers and their loved ones during the COVID-19 pandemic.

Caregiving for People with Dementia

"Dementia" is an umbrella term for a progressive, acquired brain disorder characterized first by substantial cognitive impairment that interferes with daily function of afflicted individuals. People with dementia increasingly need caregivers for high level tasks such as transportation, financial management, and medication management. As disease progresses, they need assistance with basic activities of daily living, such as toileting, feeding, hygiene, and dressing. Personality

change, psychiatric disturbances and behavioral problems are also manifestations of dementia.

Caregiving takes a toll financially, physically, and psychologically on caregivers. Often, caregivers experience isolation, loneliness [9,10] and grief [11,12]. Caregiver burden pertains to the caregiver's perceptions of the toll of caregiving on their physical, psychological, social, spiritual and financial well-being [13]. Caregivers with high burden are at increased risk for medical illness [14,15], and depression [16,17]. Major determinants of caregiver burden include low monthly income, female gender, greater hours of caregiving, low educational level, cohabitation with the patient, non-Hispanic Caucasian ethnicity, low confidence in caregiving ability, and lack of choice in being a caregiver [18,19]. Across different types of dementia, behavior problems (e.g. aggression, care refusal), and neuropsychiatric problems (e.g. agitation, delusions) are causes of early nursing home placement [20].

COVID-19 and Caregiving

The COVID-19 pandemic increases the challenges of caregiving. Job loss and furloughs cause or exacerbate financial stress. Disruption of services present barriers to care. COVID-19 affects many aspects of daily decision making, including hiring in-home help, shopping and picking up medications in person, and having loved ones over to visit. Decision-making can provoke fear, worry and guilt about exposing care recipients to COVID-19.

Caregivers from low income and/or underserved minoritized populations suffer greater risk for COVID-19 as they experience significant health disparities [21,22], as a result of structural inequities such as environmental and social hinderances (e.g. food deserts, high housing density, poor air quality, etc). Specifically, they face barriers to accessing resources, diagnostic evaluations, treatment and preventative measures [23-25]. Furthermore, lack of technology and computers creates another barrier to care as most care providers transition to telehealth to reduce exposure to COVID-19.

How can caregivers cope with increased stress during COVID-19, stay safe, and continue to provide quality care to loved ones with dementia? We propose a tri-directional approach including: 1) Education and future planning; 2) Proactively reducing or preventing increased stress in care recipients with behavioral management; and 3) Engaging in self compassion and care to fortify caregiver coping.

Education and Preparedness

Education about COVID-19: Research from prior virus outbreaks indicates that seeking emotional support and staying informed about risk are effective coping strategies for psychological distress [26]. Caregivers need to be aware of COVID-19 infection rate and risk in their immediate locality, and make decisions according to their lifestyle and any health risk factors for themselves and their loved ones [27,28]. Reliable sources of information include Center for Disease Control (CDC), WHO, county health departments, regional medical centers and COVID-19 hotlines.

Prepare for emergencies: In the event that the PWD becomes ill with COVID or a life threatening condition, advanced directives should be in place to aid the family in decision making according to their loved one's wishes. Caregivers also need advanced directives in

place for themselves. Caregivers should identify a backup caregiver, a caregiving plan, and prepare an emergency kit in the event that they become incapacitated. Emergency kits should include copies of legal and medical documents (such as power of attorney), current medications, insurance and social security cards, clothes and personal items that provide comfort to the care recipient, and an informative list of their likes and dislikes [29].

Learn about resources: Financial hardship is a reality for many caregivers even under the best of circumstances; however, it is exacerbated for those who have lost income due to the pandemic. Knowing one's entitlements for support can help reduce financial burden. The National Institute on Aging [30], caregiver advocacy groups such as The Alzheimer's Association [31], and the Association for the Advancement of Retired People [32] provide information about resources and assistance for caregivers during COVID-19. Federal, state and local governmental websites provide information about financial assistance, in-home services, low cost internet and food support.

Psychoeducation about dementia: Caregiver education about dementia and caregiving skills is essential for caregiver and patient well-being. Education and training are available over the internet. Web-based and online education and interventions reduce caregiver distress (anxiety, depression) and enhance caregiving skills and confidence [33,34]. Caregiver training and education is available through non-profit organizations, such as the Alzheimer's Association, medical centers and hospitals [35]. People without the internet can call a dementia advocacy organization related to their loved one's specific type of dementia, and speak with a counselor or reference one of the many comprehensive caregiving themed books from brick and mortar and online bookstores.

Proactive Stress Reduction in Care Recipients

COVID-19 disrupts the daily routines of caregivers and care recipients because of the limited options for socialization and cognitive stimulation during SIP. Keeping loved ones busy and fulfilled is essential to staving off agitation, boredom, and behavior problems.

Maintain routines: Daily routines create feelings of security in PWD. Make efforts to preserve as many aspects of the usual routines as possible, such as the consistent wake and bed times, meal times, exercise and social activities. An example of a routine may be: Morning - breakfast, personal hygiene, walk outdoors; Afternoon - lunch, chair exercises, 30- 45minute nap, snack, activity; Evening - dinner, activity, and bed. Putting up a daily schedule on a dry erase board in a central place or giving the care recipient a daily schedule helps ease their anxiety and can reduce repeated questioning. Tailoring activities to the cognitive level and interests of the care recipient reduces agitation [36]. For instance, care recipients who used to enjoy cooking can make a simple meal, and a gardener can help water plants. Care recipients with later stage dementia can fold towels and work simple puzzles (even if they do not solve them), play simple card games, or color. Use outdoor space, such as yards, patios, and nearby parks, for walks and exercise. Aquariums or placing bird feeders near a window provide entertainment. The internet is a valuable resource for cognitive stimulation, socializing, entertainment (movies, music, virtual tours) and for streaming exercise programs. Video visits with

other family members and friends are important for socialization and reducing isolation.

Exercise: Exercise deserves special mention as both recreation and a health maintenance activity. Exercise can improve functional activities [37], sleep [38], and mobility [39] in PWD. Some evidence suggests exercise may be beneficial for cognition [40]. Most exercises can be performed in or around the home, including walking, dancing, gardening, light weight training, chair exercises, simple yoga, stretching, Thai Chi or tossing a ball.

Connect emotionally: Caregivers and their loved ones relationships suffer due to communication problems, less mutuality and reciprocity in the relationship, and having less in common [41,42]. Find common ground for conversation and sharing experiences. Reminiscing about the past is enjoyable and doable for most care recipients because they have better long-term than short-term memory [43]. Ways to reminisce include watching old movies or TV shows and listening to nostalgic music; talking about family and childhood; looking through old photo albums; and sharing family and cultural traditions and foods that may spark fond memories.

Evaluate the household to enhance safety: Assess for the need of assistive devices, such as walkers and canes, gait belts, and grab bars. In multiple level homes, consider moving the care recipient's bedroom downstairs. Remove trip hazards like throw rugs. Lock up or remove weapons (guns, knives).

Maintain socialization: People with dementia may feel abandoned because friends and helpers cannot visit them during SIP. Care recipients will probably forget the reasons for physical distancing. If safety recommendations permit, arrange for a short social distancing outdoor visit with a loved one. Increase telephone calls and use video visits to maintain social connectedness. Ask friends and relatives to call and send greeting cards, letters and emails, and display cards so care recipients can continue to appreciate them.

Monitor Mood

People with dementia of any type have a high incidence of major depression. According to a recent meta-analysis the mean prevalence of depression in dementia ranges from 20% to 37% [44]. The symptoms of depression in PWD are similar to those in people without dementia. Symptoms include irritability, sleep disturbance, appetite loss, low mood, loss of motivation and interest, anxiety, and withdrawal. Anxiety is also common PWD, ranging from 5-16 %. Symptoms include inability to relax, and behavioral problems such as asking repeated questions, pacing, agitation, and sleep disturbance. Depression and anxiety are both very treatable in patients with dementia behaviorally and pharmacologically. Adding structure and pleasant activities can help. If symptoms persist for over two weeks, then seek a consult with a physician about pharmacological treatment.

Talking to People with Illness about COVID-19

Care recipients may not understand the concept of a pandemic or risk reduction procedures. Simplify explanations about safety, such as the purpose of masks is to protect from a bad "flu" or a "virus going around". People with dementia should avoid viewing upsetting news reports and images related to COVID-19. Dementia-related

behaviors may increase risk, thus when necessary, remind loved ones about social distancing and wearing masks. Post signs in the bathroom as reminders to wash hands. Keep hand sanitizer readily available around the home. Lastly, it is important to consistently reassure loved ones that they are safe.

Self-Care for Caregivers

Stress Reduction: In the best of times, stress is ongoing for caregivers, thus regular stress management is crucial for ongoing well-being. Unfortunately, many caregivers neglect themselves while caring for their loved one, thus caregiver self-care needs to be scheduled into each day. Self-care includes getting enough sleep, exercising, finding time to relax and finding the positive's in caregiving. Mindful meditation, relaxation techniques (e.g. deep breathing) and anger management are viable interventions for stress reduction. A recent meta-analysis found that mindful meditation has mild to moderate beneficial effects on alleviating dementia caregivers' perceived stress and improving mental health-related quality of life [45]. Mindfulness instruction is widely available on the internet, on telephone applications and in books. Brief (5 to 15 minute) breaks for engaging in deep breathing, meditation, and guided meditations through phone apps are helpful in reducing stress and anxiety.

Support groups: Support groups are major sources of education about dementia and behavioral problems, and are invaluable for normalizing feelings of sadness, anger, frustration and grief. Research has shown that support groups can improve caregiver well-being, social outcomes, and reduce caregiver stress, burden and depression [46]. Virtual support groups are an alternative to in-person support groups during the pandemic. Virtual support groups include online chats, video conferences and telephone platforms [47]. Virtual or telephone support groups can be found through a local Alzheimer's Association chapter or local medical center.

Mood Management: Depression and anxiety are two major psychological consequences of caregiver burden and stress. Caregivers should learn the signs of depression (e.g. sleep disturbance, sadness, anger, concentration problems, hopelessness, suicidal thoughts) and anxiety (e.g. restlessness, tension, worry) and address them before their situation becomes unbearable. Increasing use of alcohol and other drugs often indicate an attempt to self-medicate to reduce symptomology. Caregivers may need professional help if coping strategies and lifestyle adjustments do not alleviate or reduce mood symptoms. Anyone with increasing thoughts of death or with immediate intent and a plan for suicide requires immediate attention from a mental health professional. Under those circumstances, suicidal caregivers should call their doctor or therapist, or if not available right away, a suicide hotline. Psychotherapy, offered via video and telephone, is an empirically supported intervention for caregiver burden and depression [48]. Cognitive behavioral therapy is available through self-help books and phone applications ("apps"); but only a few phone apps tested in clinical trials demonstrated effectiveness for depression symptoms [49,50]. Manage anxiety by focusing on controllable aspects of a situation-such as practicing COVID-19 risk reduction behaviors, learning behavioral problem management skills, exercising, and getting respite. Medication for the caregiver improves depression, resilience, burden, and quality of life [51]. Medicating care recipients for memory or behavioral problems

has a modest effect on reducing caregiver burden and time spent caregiving [52].

Respite: Respite is essential for all caregivers. Respite takes the form of both short and long breaks from caregiving. During non-pandemic times, options include bringing in home help, sending the care recipient to adult day care, and utilizing residential care for short stays. Those options are less available during a pandemic because of SIP and physical distancing. COVID-19 SIP is the time for families to put aside family conflict to come together to develop a caregiving plan. The caregiving plan should play on the strengths or desires of the people involved. The plan could include sharing direct caregiving duties, shopping, housecleaning, financial management, and visiting to relieve the primary caregiver or chipping in financial support. Set-up automate bill payments and bank deposits when possible. Web cams and sound monitors allow the caregiver to have more personal space without sacrificing the ability to monitor loved ones.

Exercise: Caregivers tend to sacrifice exercise for caregiving. They have difficulty adhering to an exercise program because of time constraints. Nevertheless, exercise has positive effects on caregiver burden through stress reduction and improving the physical conditioning of caregivers [53]. Scheduling measurable exercise goals ("20-minute walking on Monday, Wednesday and Friday at 11am) will help caregivers adhere to a regimen. If caregivers cannot leave the house, other options to consider include exercising while the care recipient is napping, or exercising with the care recipient.

Cognitive Coping Strategies: Finding the positives in caregiving is a valuable emotion-focused coping strategy [54]. A recent meta-analysis found that caregivers experience an increased sense of accomplishment and feel gratitude for acquiring caregiving skills that are helpful to their loved one. Acceptance of the situation also is beneficial. Caregivers may feel more mutuality in the relationship by accepting their new role and looking for responses of gratitude and appreciation from their loved one. Some caregivers view their role as an act of love and believe that the care recipient would do the same for them if the situation were reversed. Other positives include improved family cohesion while sharing caregiving duties. Caregivers may feel a sense of purpose and personal growth through overcoming adversity, becoming more patient, caring, and sensitive.

Attend to spiritual needs: Spirituality, religious beliefs, and religious attendance are associated with better mental health in family caregivers of persons with dementia [55]. Although in-person group religious services may be suspended temporarily during COVID-19, many religious organizations stream worship services. Caregivers can also reach out to clergy via telephone. Bible study and prayer groups can occur online or via video calls.

Healthcare Providers

Practitioners are best able to treat the patient and be helpful to the family by gathering specific details about the family's caregiving situation, the family's knowledge about caregiving, and access to resources. Physicians are frequently pressed for time, however, gathering pertinent information is essential for comprehensive patient care. A pre-visit questionnaire inquiring about caregiver needs and circumstances can expedite information gathering and provide an overview of the family's unmet needs [56]. Gather

information on who is/are the caregiver(s), their relationship to the care recipient, their perceived level of stress and burden, and their willingness to provide care. It is also important to assess the health status of the caregiver, social support, transportation needs, and financial resources. Inquire about who else is in the household. Additionally, ask about how families are coping with the pandemic. Do they know how to reduce risk and obtain personal protective equipment? Is anyone in the home an essential worker who is not sheltering in place?.

Consider each family's unique culture, family dynamics, language, and level of acculturation [57,58], when assessing for caregiver stress and make recommendations for the patients and their families. The concepts of dementia and caregiving vary according to culture, and the concept of the "primary caregiver" may not be equally applicable in all cultures; therefore, interventions aimed at the family, rather than just the primary caregiver, may be more culturally appropriate [59]. Referrals to resources need to be culturally specific for the individual and their families and accessible in their community. Practitioners with limited cultural competence can consult caregiver and dementia advocacy groups for information on appropriate resources for their patients.

Conclusion

Caregiving during the COVID-19 pandemic can be fraught with additional stress for the caregiver and the care recipient with dementia due to direct threats to well-being related to the pandemic, changes in caregiving due to the limitations posed by social distancing and SIP orders and continued worsening of their loved one's condition. Caregivers will need to reappraise their caregiving situation, problem solve, and employ additional emotional and practical coping strategies. Education about caregiving and social support for the caregiver are essential to increase confidence in caregiving and reduce the caregiver's isolation. Caregivers must also make self-care a priority. Health practitioners can help families struggling with dementia by inquiring about their mental and physical health, providing education about COVID-19, and directing families to appropriate resources for enhancing caregiving, coping and the family's well-being.

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