

PERSPECTIVE

The need for psychological, caregiver-centered intervention in the time of COVID-19

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Abstract

We focus attention on problems that are affecting the informal caregivers of patients with neurodegenerative disorders in the time of COVID-19. The pandemic is increasing difficulties in the management of the frailest people and their isolation is actually even more tangible than it was in the past. The social restrictions and the lockdown of many activities are putting the system of care provided by informal caregivers on the edge of collapse. We incite the scientific community to face these concerns and provide clinicians clear indications for assisting and supporting caregivers in the care of their relatives during this period. We suggest that e-health programs could become the ideal “environment” to favor the continuity of care for patients with neurodegenerative conditions and guarantee the required support to their caregivers, both directly in terms of psychological management and indirectly for helping them in disease management.

KEYWORDS

caregivers, COVID-19, lockdown, psychological support

The outbreak of coronavirus disease 2019 (COVID-19), caused by the novel severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), has dramatically changed our lives and still represents a complex challenge for health-care systems worldwide. Quarantine, social distancing, and the lockdown of many activities have been successfully applied in several countries to limit the spread of this outbreak and to avoid the “collapse” of the hospitals. Consequently, many outpatient and inpatient health-care activities have been suspended, thus conditioning several public health problems and other disease-management difficulties. This vacuum of assistance has overwhelmed the frailest people: among them, the patients affected by chronic neurodegenerative diseases and their informal caregivers have been particularly hit by the pandemic.

The rising number of people with neurodegenerative disorders represent one of the major critical challenges for public health worldwide.¹ Currently, in the field of the neurodegenerative diseases care, a substantial part of monetary expenses is accounted by the work and the

time spent by informal caregivers for managing their relatives.² Parkinson's disease (PD), Alzheimer's disease (AD), and other neurodegenerative diseases pose a significant burden for caregivers, affecting physical, emotional, and social aspects of their quality of life.³ More than 40% of caregivers of patients suffering from PD report that their physical health had suffered as a result of caregiving, two thirds report an impact on their close or distant relationships, and almost half of people caring for AD patients had clinical or subclinical psychiatric problems.^{2,4}

Obviously, the current pandemic, together with the related social restrictions, could further worsen the caregivers' quality of life, either directly or indirectly. There are several possible adverse situations that could deteriorate the conditions of patients with neurodegenerative disease during the COVID-19 pandemic.

Helmich and Bloem⁵ discussed several short-term and long-term adverse consequences for individuals with PD that could be attributed to increased psychological stress: (1) worsening of motor symptoms,⁶

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(2) reduction of the efficacy of dopaminergic medication,⁶ and (3) impairment of compensatory mechanisms.⁷ Moreover, many patients losing their normal routine have interrupted physical activities with inevitable consequences for their well-being.⁸ Wang et al.⁹ underlined the difficulties for people living with dementia to understand information and facts about the COVID-19 pandemic and in remembering safeguard procedures, such as wearing masks.⁹ In this concern, demented patients ignoring the warnings and lacking sufficient self-quarantine measures expose themselves to higher chance of infection.⁹ Moreover, the loss of proper reference points, resulting from the sudden change in daily life as one of the consequences of the "lockdown," could affect negatively several behavioral aspects and increase neuropsychiatric symptoms, which are the first cause of caregivers' burnout.¹

These connected adversities could worsen caregivers' burden, putting society at risk of losing this crucial source of care. Therefore, the scientific community should face this concern and indicate to clinicians good practice to assist and support caregivers.

It is crucial that the different health-care services provide psychological and educational training to caregivers. Previous studies have highlighted the effectiveness of psychological, caregiver-centered interventions, such as cognitive-behavioral therapy and psychoeducational group programs (based on the World Health Organization International Classification of Functioning, Disability, and Health framework),¹⁰ for (1) increasing the self-efficacy in the management of patients' motor, cognitive, and behavioral symptoms; (2) increasing the self-control of intrusive and upsetting thoughts, in light of cultural and social beliefs; and (3) ameliorating the interpersonal relationships and communication among patient, principal informal caregiver, and the other family components.^{11,12}

Other literature data highlight the feasibility and the reliability of telehealth (i.e., the use of digital information and communication technologies to access health-care services remotely) in reaching people and to ensure the effectiveness of psychological and educational interventions.¹²

From a more general point of view, the COVID-19 pandemic could be the flywheel for creating an "e-health scenario" that has been several times advocated and proposed in the past. In this view, wireless medical networks provide platforms that would reduce the number of hospitalizations and "on-site" hospital visits, saving time and resources,¹³ as well as to reduce the risk of infection for frail people.

It is finally conceivable that the allocation of resources on "e-health" practices, favoring the continuity of care for patients with neurodegenerative conditions, guarantees the required support to their caregivers, both directly in terms of psychological management and indirectly for helping them in disease management.

CONFLICTS OF INTEREST

There are no disclosures or conflicts of interests to declare.

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REFERENCES

1. Cheng ST. Dementia caregiver burden: a research update and critical analysis. *Curr Psychiatry Rep.* 2017;19:64.
2. Prince M, Wimo A, Guerchet M, Gemma-Claire A, Wu Y-T, Prina M. World Alzheimer Report 2015: the global impact of dementia - an analysis of prevalence, incidence, cost and trends. *Alzheimer's Dis Int.* 2015;84.
3. Schrag A, Hovris A, Morley D, Quinn N, Jahanshahi M. Caregiver-burden in parkinson's disease is closely associated with psychiatric symptoms, falls, and disability. *Parkinsonism Relat Disord.* 2006;12:35-41.
4. Sansoni J, Vellone E, Piras G. Anxiety and depression in community-dwelling, Italian Alzheimer's disease caregivers. *Int J Nurs Pract.* 2004;10:93-100.
5. Helmich RC, Bloem BR. The impact of the COVID-19 pandemic on Parkinson's disease: hidden sorrows and emerging opportunities. *J Parkinsons Dis.* 2020;10:351-354.
6. Zach H, Dirx MF, Pasman JW, Bloem BR, Helmich RC. Cognitive Stress Reduces the Effect of Levodopa on Parkinson's Resting Tremor. *CNS Neurosci Ther.* 2017;23:209-215.
7. Djamshidian A, Lees AJ. Can stress trigger Parkinson's disease?. *J Neurol Neurosurg Psychiatry.* 2014;85:878-881.
8. Schirinzi T, Di Lazzaro G, Salimei C, et al. Physical activity changes and correlate effects in patients with Parkinson's disease during COVID-19 lockdown. *Mov Disord Clin Pract.* 2020;7(7):797-802.
9. Wang H, Li T, Barbarino P, et al. Dementia care during COVID-19. *Lancet.* 2020;395:1190-1191.
10. Byrne Kerry, Orange JB. Conceptualizing communication enhancement in dementia for family caregivers using the WHO-ICF framework. *Adv Speech Lang Pathol.* 2005;7(4):187-202.
11. Birkenhäger-Gillesse EG, Kollen BJ, Zuidema SU, Achterberg WP. The "more at home with dementia" program: a randomized controlled study protocol to determine how caregiver training affects the well-being of patients and caregivers. *BMC Geriatr.* 2018;18:252.
12. Cheng ST, Au A, Losada A, Thompson LW, Gallagher-Thompson D. Psychological interventions for dementia caregivers: what we have achieved, what we have learned. *Curr Psychiatry Rep.* 2019;21:59.
13. Zvikhachevskaya A, Markarian G, Mihaylova L. *Quality of Service Consideration for the Wireless Telemedicine and E-Health Services.* Budapest: 2009 IEEE Wireless Communications and Networking Conference; 2009:1-6.

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