

Saturday

Effects of the COVID-19 pandemic on caregiver burden in frontotemporal degeneration: Findings from the ALLFTD consortium

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State of the art: The COVID-19 pandemic disrupted the healthcare sector, presenting caregivers with new challenges. Evaluating the effects of the COVID-19 pandemic on caregiver burden in frontotemporal lobar degeneration (FTLD) will inform how to better support caregivers as the pandemic continues and prepare for future pandemics and disasters.

Methodology: The National Alzheimer's Coordinating Center COVID-19 Impact Survey – Co-participant questionnaire assesses the impact of COVID-19 on the well-being of caregivers of FTLD patients. The questionnaire was completed on an optional basis at ALLFTD visits. Caregivers responded according to the way they felt at the time of survey completion. The individual COVID-19 questions were analyzed for caregivers whose patients had CDR® plus NACC FTLD (FTLD-CDR) ratings.

Results: A total of 185 caregivers completed the survey during a baseline (Visit 1) assessment. As the global FTLD-CDR rating increased, caregivers admitted that the COVID-19 pandemic increasingly affected their ability to care for their FTLD patient (Kruskal-Wallis Test, $p < 0.05$). The mean FTLD-CDR rating for patients whose caregivers responded that care was easier to provide was 1.98 versus 2.47 for those who responded that care was extremely difficult to provide. Additionally, caregivers' ability to access care assistance during the pandemic, specifically respite by family or friends, paid respite by care agencies, and medical care including physician appointments differed significantly by FTLD-CDR rating (Pearson's Chi-squared test, $p < 0.05$).

Conclusion: These results indicate that the COVID-19 pandemic has impacted the caregivers of FTLD patients, and that certain aspects of pandemic-induced caregiver burden differ by FTLD severity.

Conflicts of interest

None