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PPA Tele-Savvy: Piloting an Online Intervention with Care Partners of Persons Living with Primary Progressive Aphasia

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Background: PPA brings unique challenges for caregiving families. Most evidence-based interventions available to dementia caregivers do not match their needs for tailored psychosocial support.

Methodology: This pilot study is an adaptation of Tele-Savvy, an evidence-based online psychoeducation program. The goals of PPA Tele-Savvy: (1) address the communication and other cognitive and behavioral challenges facing informal caregivers of those living with PPA as the disease progresses and (2) help these caregivers achieve competence in their role. Nine spousal caregivers were recruited to this pilot, which included seven 90-minute weekly videoconference sessions and homework assignments. We engaged in a process of formative evaluation to assess and integrate feedback throughout the intervention. We also assessed the pre/post effects on PPA knowledge, mood, caregiver burden, perceived stress, competence, quality of life and relationship and held a focus group 4 weeks post-intervention.

Results: Initial results indicate notable reduction in caregiver burden and improvement in the couple relationship and care partner quality of life. Pre/post-measures showed increased observations of and reactions to disruptive and depressive behaviors of persons living with PPA. Qualitative review suggests participants derived benefits from disease education, interaction with other PPA care partners, and prompts to reflect on current/future caregiving considerations. Participants reflected that greater attention to the emotional aspects of caregiving, more opportunities to connect with others in the group, and increased time in the program would improve future iterations.

Conclusion: This study demonstrates the feasibility and value of offering an online PPA caregiver intervention tailored to meet their specific needs.

Conflicts of interest

The author has no disclosures.