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POSTER ABSTRACT

Caring for patients with Complex Brain Disorders: a mixed methods investigation of care partner burden at the Brain Medicine Clinic

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Stefanie Tan[1], Katherine Skowronski, Sara Hanafi, Sarah Levitt, Sara Mitchell, Cheryl Cheuk Yan Leung[3]

1: Sunnybrook Research Institute, Canada
3: King's College London, United Kingdom
2: University of Toronto, M5R1P1

Background: and objectives : Care partners of patients with complex brain disorders are particularly vulnerable to care partner burden due to the multifaceted nature of these conditions that necessitate the coordination of care across health and community-based care providers. The Brain Medicine Clinic at the Sunnybrook Health Sciences Centre, Toronto, Canada is a novel clinical model that provides a one-stop shop for patients that facilitates the integration of care by a multidisciplinary team of physicians (e.g., geriatrics, psychiatry, neurology, pediatrics, and physical medicine & rehabilitation (PM&R)), neuropsychologists, and patient navigation to deliver timely diagnosis and collaborative holistic care for patients with complex brain disorders. This study explores the prevalence of care partner burden and assesses the impact of the introduction of an embedded patient navigator for caregivers of the patient population at an interdisciplinary specialist clinic for people with complex brain disorders.

Approach: This is a cross-sectional mixed-methods study (Winter to Autumn 2025) to explore the experiences of care partners of patients at the Brain Medicine Clinic at Sunnybrook Health Sciences Centre in Toronto, Canada. All patients with care partners attending the clinic in Spring 2025 and Autumn 2026 were approached to take part in the study. We utilize standardized clinical tools (i.e., Zarit Burden Interview 12; WHO-5 Well-Being Index; Lawton-Brody scale; and Katz Index of Independence) to collect self-reported measures of care partner burden (n=50-60). Quantitative data will be analyzed in SPSS 20 to draw out descriptive statistics (Winter 2026). All respondents are invited to take part in focus groups (n=20-25).

We map qualitative data against a conceptual framework, developed in partnership with the clinic's steering group which includes people with lived experiences as caregivers and social workers, about care partners to understand the benefits, enabling factors and barriers to improving care partner burden in a novel integrated care model.

Results: The interim results suggest there is a high prevalence of care partner burden amongst care partners of patients with complex brain disorders, an underserved population that struggle to access health services without external support. Key factors shaping care partner experience include interactions with the healthcare system, their wellbeing, the implications of their role, interactions with the care recipient, as well as pervasive uncertainty.

Care partners identified the need for resources, education and communication for support and agree that the introduction of an embedded patient navigator in Autumn 2024 has potential to improve the care pathway by assisting care partners to navigate the healthcare system and access available resources.

Implications: Patient navigation has been shown to be effective in other complex populations such as dementia patients and should be further studied in patients with complex brain disorders. Given the risk of suboptimal mental health outcomes in care partners, identifying cost-effective interventions to mitigate care partner burden is paramount. This research aims to share key findings from a bottom-up initiative to transform the pathway of care for patients with complex brain disorders at the tertiary care setting to advance health services for patients with complex brain disorders and their care partners.