

Barriers to Clinical Care in Frontotemporal Dementia and Related Disorders: Patients and Caregivers' Journey in the Canadian Healthcare System

Alexandrine Martineau, MBBS, FRCPC, MSc^{1,2,3}, Miguel Conant, BSc^{1,2,3}, Philippe Desmarais, MD, FRCPC, MHSc^{1,2,3}

1. Centre Hospitalier de l'Université de Montréal (CHUM), Montréal, Québec, Canada
2. Centre de recherche du Centre Hospitalier de l'Université de Montréal (CRCHUM), Montréal, Québec, Canada
3. Faculté de Médecine, Université de Montréal, Québec, Canada.

BACKGROUND

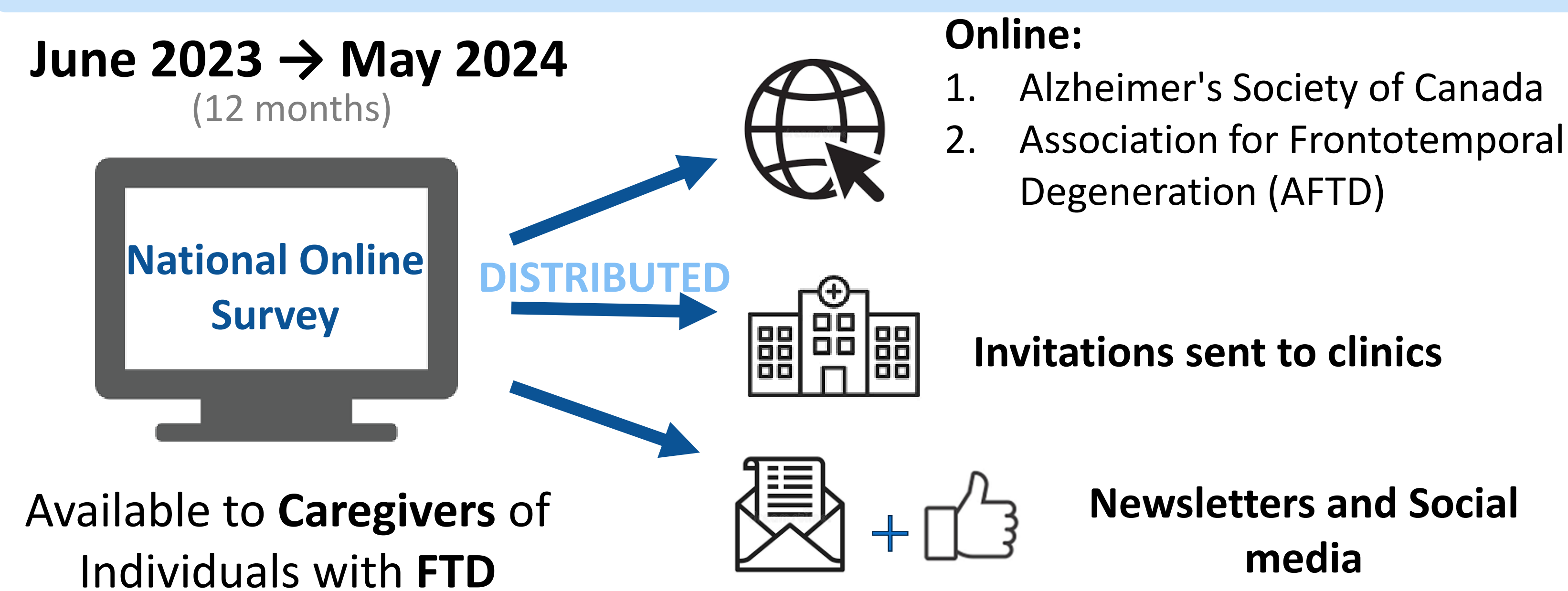
- **Frontotemporal dementia (FTD)** and related disorders (i.e., behavioural variant FTD [bvFTD], primary progressive aphasia [PPA], progressive supranuclear palsy [PSP], corticobasal syndrome [CBS]) are the **second most common neurodegenerative diagnoses of early-onset dementia** after Alzheimer's disease (AD), and the **third most common neurodegenerative diagnoses of late-onset dementia** after AD and Lewy body dementia (LBD)¹.
- **Navigating the healthcare system** to obtain an accurate diagnosis and care can be **challenging** for individuals with frontotemporal dementia (FTD) and their caregivers.
- A better understanding of their journey may help identify and mitigate barriers to optimal care.

OBJECTIVES

- 1) To gain insight into the journey of individuals with FTD in the Canadian healthcare system with regard to obtaining a diagnosis and care;
- 2) To gain insight into the journey of FTD caregivers, notably their burden related to caregiving.

METHODS

June 2023 → May 2024
(12 months)



RESULTS

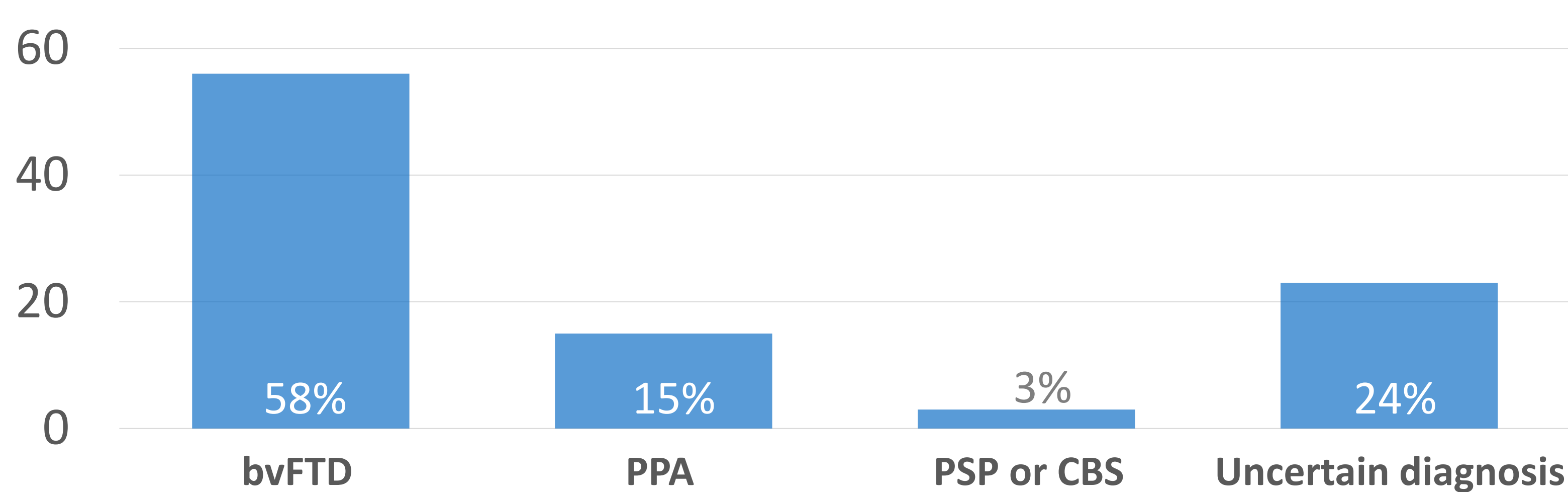


Survey completed by **97 caregivers**

Respondent Characteristics:

- **83% females**, 17% males
- **60% spouses**, 32% children, 7% other relatives, 1% others
- Mean (SD) duration of caring for their loved one of **5.7 (5.1) years**

Figure 1. Diagnosis of Loved One



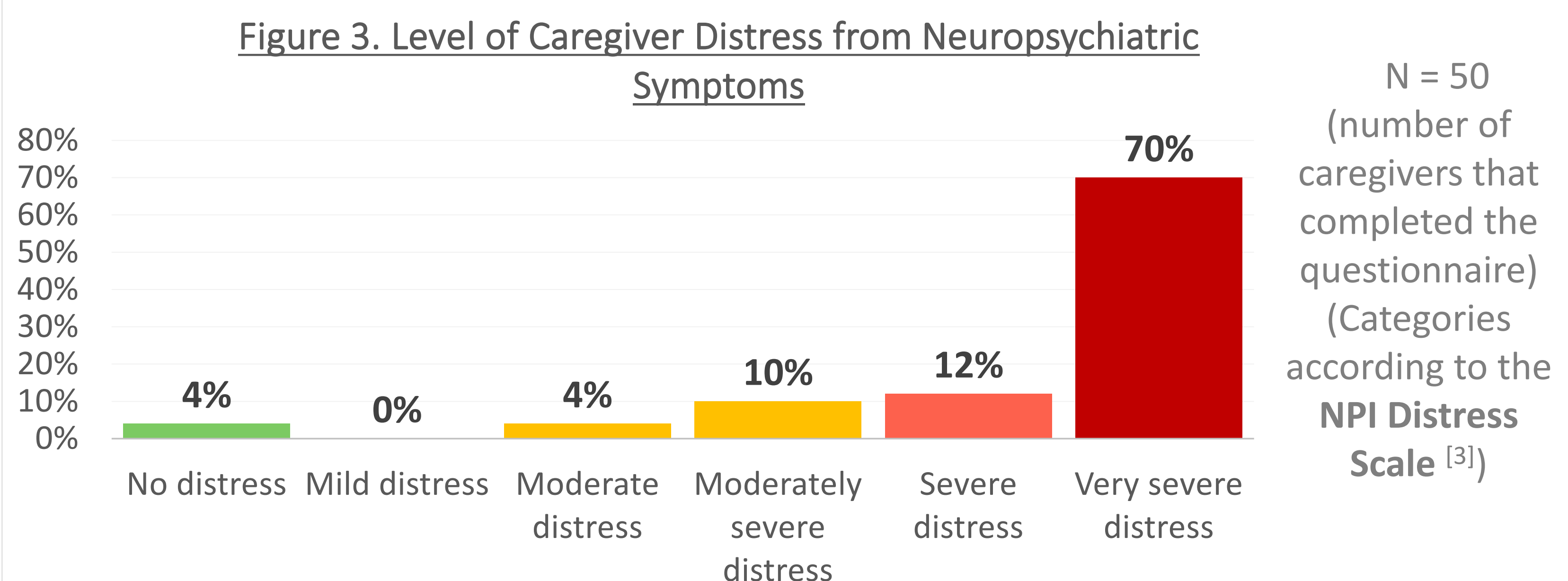
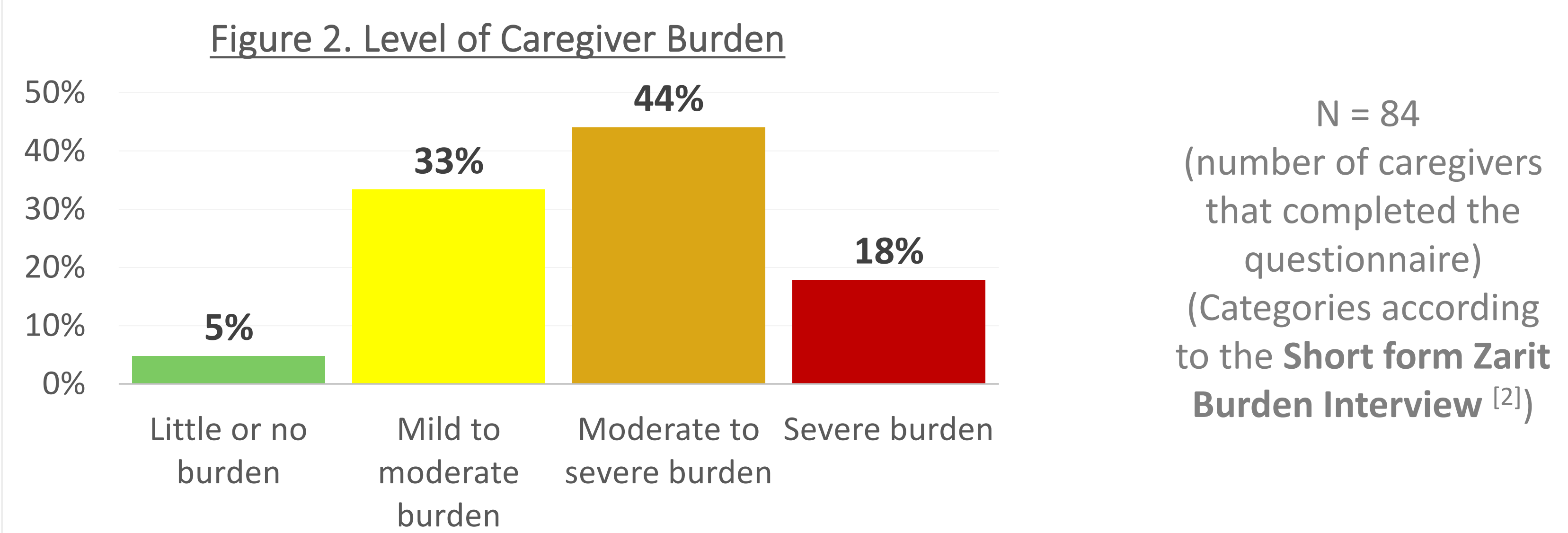
Journey To Diagnosis:

- Mean (SD) time between onset of first symptoms and final diagnosis: **3.0 (4.5) yrs**
- Mean (SD) number of clinical visits before obtaining diagnosis: **7.0 (8.5) visits**
- Caregivers reported a mean (SD) number of **3 (1.6) different physicians** were consulted before receiving a diagnosis
- A **different diagnosis** prior to FTD was reported by 57% of caregivers, most often a **psychiatric disorder (24%)** or **Alzheimer's disease (11%)**

Reported barriers to diagnosis:

- Lack of knowledge and awareness of first line workers about the disorder (17%)
- Limited access to specialized care (17%)
- Loved one not wanting to consult (12%)

Caregiver Burden:



- 74% of caregivers reported not being formally assessed throughout their journey in the healthcare system for caregiver burden.

DISCUSSION

- Our survey respondents were, in majority, **female spouses** in a caregiving role, that interacted daily with their loved one for the last 6 years.
- Most loved one's had a diagnosis of bvFTD. Of note, a **great proportion (24%) of respondents didn't know or were uncertain of their loved one's exact FTD diagnosis**, highlighting the complexity of FTD and related disorders.
- The current difficulties faced by patients and their caregivers in the Canadian health care system were highlighted by:
 - The process of receiving a FTD diagnosis requires multiples years, clinic visits, and different physicians.
 - Most (**57%**) respondents' loved ones had a different diagnosis prior to FTD.
- The barriers to diagnosis identified by caregivers included: lack of knowledge and awareness by first line workers, limited access to specialized care, and limited cooperation from their loved ones.
- Most caregivers reported experiencing **moderate to severe caregiver burden** and **very severe distress** from their loved ones FTD neuropsychiatric symptoms.

CONCLUSIONS

The barriers identified by our study can be addressed by increasing public, clinicians, and decision-makers' awareness on FTD and improving access to specialized care in Canada.

NEXT STEPS:

Knowledge translation of findings via various formats and channels to maximize impact.

ACKNOWLEDGMENTS :

The Engagement of People with Lived Experience of Dementia (EPLD) program.

[1] Coyle-Gilchrist ITS, Dick KM, Patterson K, et al. Prevalence, characteristics, and survival of frontotemporal lobar degeneration syndromes. *Neurology*, 2016; 86 (18): 1736-1743.
[2] Gratao ACM, Brigola AG, Ottaviani AC, Luchesi BM, Souza ÉN, Rossetti ES, de Oliveira NA, Terassi M, Pavarini SCI. Brief version of Zarit Burden Interview (ZBI) for burden assessment in older caregivers. *Dement Neuropsychol*, 2019 Jan-Mar; 13 (1): 122-129.
[3] Cummings JL, Mega M, Gray K, Rosenberg-Thompson S, Carusi DA, Gornbein J. The Neuropsychiatric Inventory: comprehensive assessment of psychopathology in dementia. *Neurology*, 1994 Dec; 44 (12): 2308-2314.

Funding: Dr. Desmarais is a member of Team 13 - Frontotemporal dementia, which is a part of the Canadian Consortium on Neurodegeneration in Aging (CCNA). The Canadian Consortium on Neurodegeneration in Aging is supported by a grant from the Canadian Institutes of Health Research with funding from several partners.