

Canadian Healthcare Providers' Perceptions on Accessibility of Diagnostic Tools and Specialized Resources for Frontotemporal Dementia and Related Disorders

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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)^[1].
- Individuals with FTD are frequently misdiagnosed initially and obtaining a timely accurate diagnosis may be hindered by access issues to specialized resources.

OBJECTIVES

- 1) To obtain the perceptions of Canadian healthcare providers on the accessibility of diagnostic tools for the diagnosis of FTD and specialized resources;
- 2) To assess whether perceived access barriers vary according to geographical factors.

METHODS

June 2023 → May 2024
(12 months)



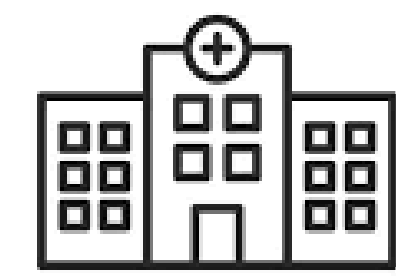
National Online Survey

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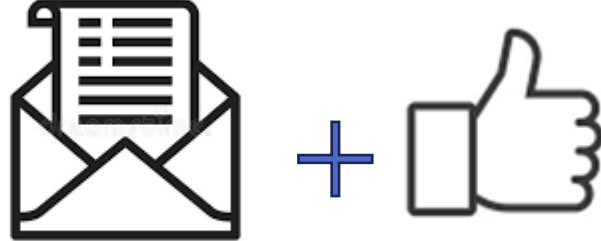


Online:

1. Alzheimer's Society of Canada
2. Association for Frontotemporal Degeneration (AFTD)



Invitations sent to clinics



Newsletters and Social media

Developed for and available to **Healthcare Providers** of individuals with **FTD** and related disorders

- The study was approved by the CRCHUM research ethics board

RESULTS



Survey completed by **141 Healthcare Providers**

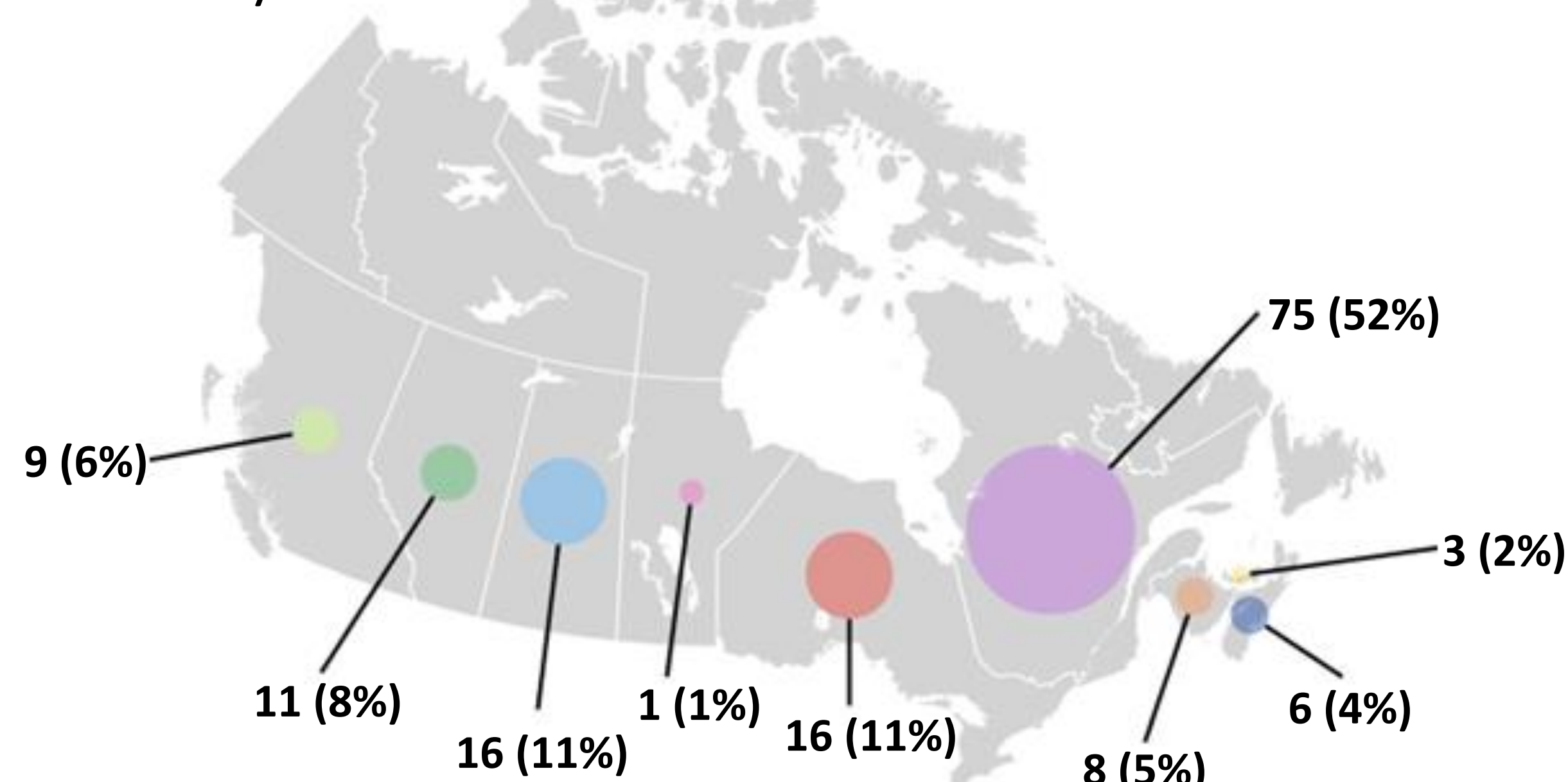
Respondent Characteristics:

- **Occupation, N (%)**

Physicians	55 (39%)
Nurses	43 (30%)
Psychologists	11 (8%)
Social Workers	11 (8%)
Another Occupation	12 (5%)
- **Experience, in years, Mean (SD)** 11.2 (9)
- **Worked in University-Affiliated Centers, N (%)**

Yes	80 (57%)
No	61 (43%)

Figure 1. Geographic Distribution of Study Participants by Province and Territory



Access to Diagnostic tools:

- **Brain Imaging,**
 - 60% agreed/strongly agreed with having an easy access to MRI;
 - 43% agreed/strongly agreed with having an easy access to FDG-PET scan;
 - 12% agreed/strongly agreed with having an easy access to amyloid PET scan.
- **Genetic testing,**
 - 30% agreed with having easy access to genetic testing.

Comparing Perceived Patient Access and Support: University Affiliated vs. Non-University Affiliated Clinicians

Table 1. Comparison of Perceived Patient Access and Support Services: University-Affiliated (N=70) vs. Non-University-Affiliated Clinicians (N=45) (% represents the proportion of healthcare providers that agreed with the statement).

My patients have...	University-Affiliated (%)	Non-University-Affiliated (%)
Easy access to MRI	66%	50%
Easy access to FDG-PET brain scan	59%	8%
Easy access to specialized clinics	85%	53%
Easy access to SPECT brain scan	21%	11%
Easy access to PET Amyloid brain scan	16%	0%
Easy access to multidisciplinary teams	80%	67%
Cognitive assessment every 12 months	74%	47%
Caregiver burden assessment	70%	53%
Access to information resources	83%	69%
Access to counseling and support	51%	44%
(and their caregiver) Access to research opportunities	8%	17%

- Respondents who worked in university-affiliated centres reported more often having an easy access to FDG-PET scan and to specialized clinics than respondents who worked in other centres (59% vs 8%, $p < 0.0001$; and 85% vs 53%, $p = 0.0036$). Similar disparities were noted between respondents working in urban settings and those working in suburban/rural settings.

DISCUSSION

- Our survey respondents included healthcare providers from across all Canadian provinces and different occupations that provide care to patients with FTD and related disease.
- **University-affiliated settings** generally provide better access to diagnostic tests, specialized clinics, and multidisciplinary teams, and conduct more frequent cognitive and independence assessments.
- **Non-university-affiliated settings** excel in providing information resources for caregivers.
- Both settings exhibit significant limitations in patient and caregiver access to research opportunities and discussions about these opportunities, indicating a common area for improvement.

CONCLUSIONS

Access to diagnostic tools and specialized resources for the investigation and management of individuals with FTD is systematically perceived as limited, with healthcare providers working in non-academic and suburban/rural settings reporting more challenging access.

NEXT STEPS:

Knowledge translation of these findings, along side the findings of the caregivers survey, via various formats and channels to maximize impact.

[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.

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