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# Access to Dementia Services in a Minority Situation: the Case of Francophones in Ontario, Canada

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L. Garcia <sup>1,2</sup>, M-H Chomienne <sup>2,3,4</sup>, M-A Cadieux <sup>2,5</sup>, E. Farmanova <sup>6</sup>, L. McCleary <sup>7</sup>, F. Molnar <sup>2,4,8</sup>, M. Agapitos <sup>1</sup>, W. Dalziel <sup>4,8</sup>, L. Khoury <sup>4,9</sup>, V. French-Merkley <sup>4,5,9</sup>, J. Joanisse <sup>4,5,9</sup>

<sup>1</sup> Interdisciplinary School of Health Sciences, University of Ottawa, <sup>2</sup> Bruyère Research Institute, <sup>3</sup> Institut de recherche de l'hôpital Montfort, <sup>4</sup> Faculty of Medicine, University of Ottawa, <sup>5</sup> Bruyère Continuing Care, <sup>6</sup> Population Health Program, University of Ottawa, <sup>7</sup> Brock University, St. Catharines, <sup>8</sup> The Ottawa, <sup>9</sup> Montfort Hospital, Ottawa, Canada

## Canadian Institutes Instituts de recherche of Health Research en santé du Canada

## Background

## Champlain Local Health Integration Network

(includes Ottawa, Capital of Canada)

- Total population 1,230,655;
- Senior Population 14% (25% by 2036);
- English as mother tongue: 66.8%;
- French as mother tongue: 18.8%.

# LAW GIVES RIGHT TO RECEIVE SERVICES IN FRENCH IN DESIGNATED GOVERNMENT AGENCIES (1986)

Dementia profile 18,400 people with Alzheimer's or related disorders in Champlain region

- At least 3,100 new cases each year;
- 64% not formally assessed and/or diagnosed early enough;
- 60% have 3 + chronic conditions.

Champlain Integration Health Service Plan 2013-2016 (statistics 2011)

Population characteristics for Champlain Health Link Areas (2013)

# DIAGNOSIS IS DEPENDENT ON COMMUNICATION/ LANGUAGE

#### **Research Questions**

- Are trajectories the same between French and English speaking people with dementia?
- How important is it for Francophones to access services in French?
- How does one access dementia-related information?
- How are the relationships with health professionals characterized by people with dementia and their caregivers?
- What are the suggestions for the improvement of services?

## Methods

## Chart audits

- in specialty clinics for dementia (i.e. first visit, reason for referral, language of preference for services, language communicated with specialist, clinical exam and results);
- in family physician offices (i.e. language used with physician, date of first symptoms, follow-up dates, tests completed and results, date of referral to specialty clinic);

## Semi-structured interviews with caregivers and persons with dementia

 30-90 minutes, face-to-face, recorded, transcribed, analyzed in NVivo,. Attention given to language issue.

## Inclusion criteria

- 50+ at time of diagnosis in clinic;
- Diagnosis confirmed between January 1, 2007 and February 2013;
- Contact person identified in chart
- Identification in charts as primarily Francophone (FR) or Anglophone (EN).

#### Results

- N = 54 (30 Francophones; 24 Anglophones); Age 78 (SD: 9.2 yrs); 31 F, 23 M;
- Demographics: No significant difference between FR and EN;
- Most common diagnosis is Alzheimer's disease, followed by mixed dementia;
- No significant difference in severity between FR and EN;
- Differences in wait times between FR and EN are not statistically significant Note: small sample size.

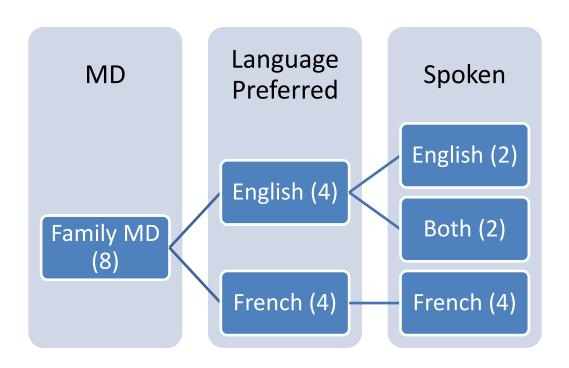


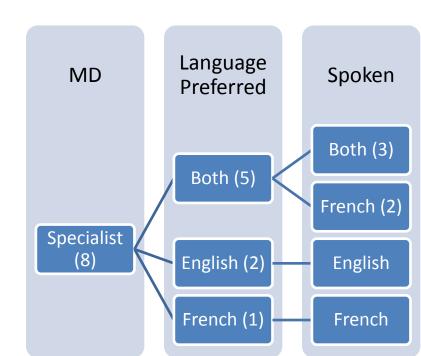
	Average Wait Time in Months (SD)	
	1st symptoms - Referral	Referral - Visit
FR	23.67 (15.52)	3.46 (2.67)
EN	9.00 (7.61)	3.35 (2.30)

## PARTICIPANT INTERVIEWS: N = 26 (12 EN; 14 FR)

### Language of service

- Preferred English? All services were received in English;
- Preferred French? Only 2/10 who preferred French received ALL services in French. Of the remaining 8 who preferred services in French, the distribution was as follows:





## CAREGIVERS SPEAK ENGLISH BUT PERSON WITH DEMENTIA DOES NOT

Need French for tests – willing to wait

- Caregiver adapts to the language spoken by the health professional;
- Many of the physicians who don't prefer to speak French make an effort to communicate in French or bilingually.

## **Getting information**

- Both EN and FR seek information through internet, pamphlets, Alzheimer Society;
- Problems in accessing information through coordinating community body (CCAC) in both FR and EN;
- FR consult family openly and for support; EN for practical reasons.



## Relationships with physicians

- Similar trajectories between EN and FR, but some FR continue to see family physician for dementia after consulting specialist;
- Many FR and EN have long-term (15+ year)
   relationships with family physician;
- Both FR and EN felt comfortable with and understood the information given by their family physician;
- EN reported positive relationships with specialists;
- Some FR reported difficulties relating with their specialists.

#### Results

### Suggestions for dementia care

- More information about long-term care (LTC);
- Better communication across pro in the system;
- More information about dementia;
- Improved individualized care;
- Inclusion of caregivers;
- Improved access to government agencies; better understanding of the repercussions of dementia;
- More opportunities for socialization for both people with dementia and their caregivers.

## **Suggestions for Services to Francophones**



- "I'm impressed we even HAVE services";
- A place to socialize with other Francophones;
- Use what's there and insist on it being French;
- LTC: more services, more homes, more nurses, more knowledge about dementia, all in FRENCH.

## Conclusions

Trajectory similar

Relationships good

Getting information

Getting information

What about when the PWD is alone? What does this say about person centred care?

This was a catalyst study. Would it be different with more participants?

Same results with services other than medical?

A prospective study?

Other minorities?

## For additional information

Linda Garcia, PhD,
Interdisciplinary School of Health Sciences
University of Ottawa

Igarcia@uottawa.ca

<u>Picture credit:</u>
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