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# Health Surveillance of Community-Dwelling People with Dementia and their Caregivers

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#### **BACKGROUND**

## **Context:**

The health and experiences of people living with dementia and their caregivers are often intertwined. However, few studies have explored the nature of this relationship while considering the well-being of both parties simultaneously<sup>1,2</sup>

#### **Objective:**

To examine how the health of caregivers interacts with that of people living with dementia

#### **METHODS**

# **Study Design/Population:**

A prospective cohort study of 177 dyads of community-dwelling people living with dementia and their caregivers

#### Persons-living-with-Dementia

Identified based on the Canadian Primary Care Sentinel Surveillance Network (CPCSSN) case definition<sup>3</sup> and validated by participating healthcare providers (figure 1)

#### Caregivers:

Identified by participating healthcare providers (figure 1)

# **Data Sources:**

#### Clinical Records from Electronic Medical Records (EMRs):

- CPCSSN routinely extracts, de-identifies and standardizes patient health data from electronic medical record (EMR) systems of participating primary care providers across Canada
- 8 out of 13 CPCSSN networks contributed data for this study (figure 2)

#### **Data Analysis:**

Linked CPCSSN dementia dyad data were assembled and analyzed descriptively using SAS 9.4

#### **Outcomes:**

#### Demographics

age, sex, location

Health outcomes

healthcare utilization, CPCSSN-defined comorbidities (osteoarthritis, depression, chronic kidney disease, hypertension, dyslipidemia)

## Risk factors

- use and misuse of alcohol, smoking, BMI
- Lived experiences of dyads
- narrative documentary

## REFERENCES

- Lilly MB, Robinson CA, Holtzman S, Bottorff JL. Can we move beyond burden and burnout to support the health and wellness of family caregivers to persons with dementia? Evidence from British Columbia, Canada. Health & Social Care in the Community. 2012;20(1):103
- Government of Canada Invests in Dementia Data and Community-Based Projects [press release]. Ottawa, ON: Public Health Agency of Canada, 2021-01-21 2021.
- CPCSSN Team, Case Definitions: Canadian Primary Care Sentinel Surveillance Network (CPCSSN), Version 2022-Q4. February 6, 2023.

#### Deidentified health data **CPCSSN** extracted twice a year by records of regional networks linked dyads **EMR CPCSSN** Repository **Dementia Dyad** cleaned, coded, **Systems** Surveillance standardized data assigned a CPCSSN ID Dyads linked to **CPCSSN** data using dyads Community EMR IDs & CPCSSN Clinics Collects health Eligible data collected for **Dyads** administrative

#### FIGURE 1:

Process map for dyad identification and linking in CPCSSN data

#### **ACKNOWLEDGEMENT**

purposes

We would like to acknowledge all the community primary care clinics and members of the patient and provider advisory committee for their valuable time and contribution.

#### TABLE 1: DEMOGRAPHIC CHARACTERISTICS OF DYADS

<b>Dyad Characteristics (N=354)</b>	Caregiver (n=177)	Care-recipient (n=177)
<ul><li>Age in years (mean (SD))</li></ul>	68.3 (15.7)	82.1 (9.8)
<ul><li>Sex (n, %)</li></ul>		
• Female	110 (62.1)	107 (60.5)
• Male	67 (37.9)	70 (39.5)
<ul><li>Location (n,%)</li></ul>		
• Rural	17 (9.6)	15 (8.5)
• Urban	158 (89.3)	159 (89.8)



Dementia: You Can Make A Difference / Démence : vous pouvez faire une différence

> A short narrative documentary featuring people living with dementia and their caregivers sharing their experiences

Follow the link:

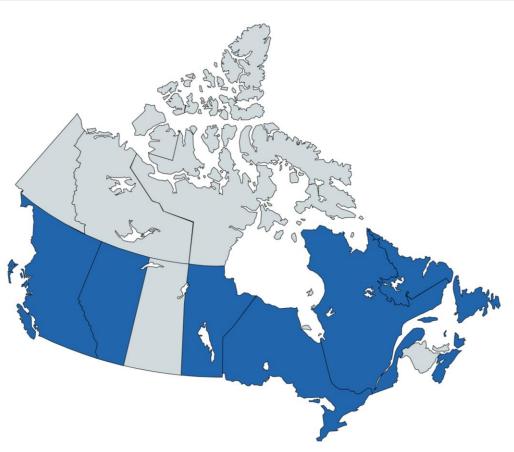
https://www.youtube.com/watch?v=7pj9H2Ntb1U

Scan the QR Code



# FIGURE 2:

The eight CPCSSN networks that are contributing data to this project from left to right are BC-CPCSSN, SAPCReN, MaPCReN, EON, OPEN, RRSPUM, MaRNet & APBRN



### TABLE 2: HEALTH OUTCOMES BEFORE AND AFTER DEMENTIA DIAGNOSIS

Dyad Characteristics (N=354)	Caregiver (n=177)		Care-recipient (n=177)		CPCSSN Controls (n=508)
	<b>Before Dementia</b>	After Dementia	<b>Before Dementia</b>	After Dementia	
<ul> <li>Healthcare Utilization (mean (SD))</li> </ul>	15.0 (15.2)	17.2 (16.1)	18.3 (14.4)	19.9 (16.7)	15.3 (13.3)
o BMI (n, %)					
<ul> <li>Underweight</li> </ul>	3 (1.7)	3 (1.7)	4 (2.3)	3 (1.7)	11 (2.2)
• Normal	38 (21.5)	42 (23.7)	45 (25.4)	67 (37.9)	83 (16.3)
<ul> <li>Overweight</li> </ul>	48 (27.1)	56 (31.6)	56 (31.6)	44 (24.9)	109 (21.5)
• Obese	57 (32.2)	49 (27.7)	40 (22.6)	40 (22.6)	110 (21.7)
<ul><li>Comorbidities (n, %)</li></ul>					
<ul> <li>Dyslipidemia</li> </ul>	92 (52.0)	111 (62.7)	115 (65.0)	129 (72.9)	298 (58.7)
<ul> <li>Osteparthirtis</li> </ul>	32 (18.1)	51 (28.8)	45 (25.4)	69 (39.0)	105 (20.7)
<ul> <li>Hypertension</li> </ul>	73 (41.2)	87 (49.2)	94 (53.1)	114 (64.4)	226 (44.5)
<ul> <li>Depression</li> </ul>	48 (27.1)	67 (37.9)	62 (35.0)	85 (48.0)	153 (30.1)
<ul> <li>Chronic Kidney Disease</li> </ul>	25 (14.1)	39 (22.0)	54 (30.5)	74 (41.8)	89 (17.5)
<ul> <li>Current Risk Factors (n, %)</li> </ul>					
<ul> <li>Alcohol Use &amp; Abuse</li> </ul>	75 (42.4)	100 (56.5)	70 (39.5)	100 (56.5)	
• Smoking	15 (8.5)	15 (8.5)	16 (9.0)	18 (10.2)	

#### CONCLUSION

Important outcomes such as increased healthcare use and an increased prevalence of comorbidities in dyads after a dementia diagnosis and compared to the control population were observed. Results provide a valuable opportunity to further investigate the needs of these dyads.

























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