



Understanding and Improving the Care of Older Adults Living with Dementia Across Four Canadian Provinces during the COVID-19 Pandemic: A Mixed-Methods Study to Inform Policy and Practices Améliorer les soins aux personnes âgées atteintes de la maladie d'Alzheimer et d'autres troubles neurocognitifs majeurs dans quatre provinces du Canada pendant la pandémie de COVID-19 : une étude mixte pour informer les politiques et les pratiques

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Résumé de l'article

Introduction : La pandémie de COVID-19 a eu de graves conséquences pour les personnes qui présentent des vulnérabilités, particulièrement celles avec un trouble neurocognitif majeur (TNM). Ces dernières risquent à la fois d'avoir une infection grave et de voir leur accès aux soins de santé et services sociaux compromis. **Objectifs** : Décrire le protocole de notre étude qui vise à :

1) Mesurer l'impact de la pandémie sur l'utilisation des services de santé et des services sociaux, la mortalité, l'infection à la COVID-19 des personnes avec un TNM, lorsque possible, à la fois dans la communauté et dans les établissements de soins de longue durée, comparativement à avant la pandémie, 2) Comprendre les besoins perçus et les comportements relatifs à l'utilisation des services de santé des personnes avec un TNM et des proches aidants, et les expériences des personnes avec un TNM, proches aidants et médecins avec les services de santé et sociaux, et 3) Générer et diffuser des recommandations fondées sur des données probantes portant sur des stratégies efficaces pour faire face à la pandémie actuelle et se préparer aux vagues subséquentes.

Méthodes : Une étude à méthodes mixtes convergentes avec approche participative réalisée dans 4 provinces canadiennes. Objectif 1 : nous ferons une étude de cohorte observationnelle rétrospective dans laquelle nous mesurerons la mortalité (toutes causes ; liées à COVID-19), l'utilisation des services de santé, et les taux d'infection dans des banques de données administratives. Objectif 2 : nous ferons une étude de cas multiple explicative, dans laquelle nous conduirons des entretiens semi-structurés et des questionnaires auprès des personnes avec TNM, proches aidants et des cliniciens. Objectif 3 : nous intégrerons les résultats des 2 premiers objectifs à l'aide d'une méta-matrice et conduirons un dialogue délibératif avec des décideurs, gestionnaires, personnes avec TNM, proches aidants et, cliniciens.

Impact et conclusion : Ce projet permettra de comprendre l'impact de la pandémie sur les personnes avec TNM et proches aidants canadiens et de souligner les domaines à améliorer.

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Understanding and Improving the Care of Older Adults Living with Dementia Across Four Canadian Provinces during the COVID-19 Pandemic: A Mixed-Methods Study to Inform Policy and Practices

Améliorer les soins aux personnes âgées atteintes de la maladie d'Alzheimer et d'autres troubles neurocognitifs majeurs dans quatre provinces du Canada pendant la pandémie de COVID-19 : une étude mixte pour informer les politiques et les pratiques

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Keywords

dementia;
health and
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use; COVID-19;
mixed-methods
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Abstract

Introduction: The implications of the COVID-19 pandemic are far reaching for persons living with dementia (PLWD) in the community and in long-term care (LTC), as they are among the most vulnerable. PLWD are at risk for severe COVID-19 and a disruption in accessing supportive and health care due to the confinement measures. **Objectives:** 1) To measure the impact of the pandemic on health and social services use, mortality, COVID-19 infection where possible of PLWD both in the community and in LTC facilities compared to before the pandemic; 2) To understand PLWDs' and care partners' perceived needs, behaviours related to health service use and the experiences of PLWD, care partners, and physicians with health and social services; 3) To generate and disseminate evidence-based and actionable recommendations on effective strategies to address the current pandemic and prepare for subsequent waves. **Methods:** A convergent mixed-methods design with a participatory approach in 4 Canadian provinces. Objective 1 will use a retrospective observational cohort design to examine administrative health data. Outcomes will include mortality (all-cause; COVID-19 related), health service use and, where possible, infection rates. Objective 2 will use an explanatory multiple case study, with surveys and semi-structured interviews to explore the experiences of PLWD and care partners using health and social services and the role of sociodemographic factors. The third, knowledge translation objective will integrate these results using a deliberative dialogue with key stakeholders (decision-makers, healthcare managers, PLWD, care partners, and clinicians) to develop and disseminate evidence-based recommendations for practice and policy. **Impact and conclusion:** This project will provide an understanding of the impact of the COVID-19 pandemic on PLWD and care partners in Canada and highlight areas for improvement.

Résumé

Introduction : La pandémie de COVID-19 a eu de graves conséquences pour les personnes qui présentent des vulnérabilités, particulièrement celles avec un trouble neurocognitif majeur (TNM). Ces dernières risquent à la fois d'avoir une infection grave et de voir leur accès aux soins de santé et services sociaux compromis. **Objectifs :** Décrire le protocole de notre étude qui vise à : 1) Mesurer l'impact de la pandémie sur l'utilisation des services de santé et des services sociaux, la mortalité, l'infection à la COVID-19 des personnes avec un TNM, lorsque possible, à la fois dans la communauté et dans les établissements de soins de longue durée, comparativement à avant la pandémie, 2) Comprendre les besoins perçus et les comportements relatifs à l'utilisation des services de santé des personnes avec un TNM et des proches aidants, et les expériences des personnes avec un TNM, proches aidants et médecins avec les services de santé et sociaux, et 3) Générer et diffuser des recommandations fondées sur des données probantes portant sur des stratégies efficaces pour faire face à la pandémie actuelle et se préparer aux vagues subséquentes. **Méthodes :** Une étude à méthodes mixtes convergentes avec approche participative réalisée dans 4 provinces canadiennes. Objectif 1 : nous ferons une étude de cohorte observationnelle rétrospective dans laquelle nous mesurerons la mortalité (toutes causes ; liées à COVID-19), l'utilisation des services de santé, et les taux d'infection dans des banques de données administratives. Objectif 2 : nous ferons une étude de cas multiple explicative, dans laquelle nous conduirons des entretiens semi-structurés et des questionnaires auprès des personnes avec TNM, proches aidants et des cliniciens. Objectif 3 : nous intégrerons les résultats des 2 premiers objectifs à l'aide d'une méta-matrice et conduirons un dialogue délibératif avec des décideurs, gestionnaires, personnes avec TNM, proches aidants et, cliniciens. **Impact et conclusion :** Ce projet permettra de comprendre l'impact de la pandémie sur les personnes avec TNM et proches aidants canadiens et de souligner les domaines à améliorer.

Mots-clés

troubles
neurocognitifs
majeurs;
utilisation des
services de
santé et des
services sociaux;
COVID-19;
méthodes
mixtes;
protocole

INTRODUCTION

In Canada, and the world more broadly, there is an urgent need to effectively mitigate the rapid spread of COVID-19 and minimize its direct and indirect impacts on persons living with dementia (PLWD) and care partners (Mok et al., 2020). This is essential for those residing in long-term care (LTC) and also community settings. There are more than 564,000 Canadians living with dementia (Alzheimer Society of Canada, 2016). PLWD are particularly vulnerable to both the direct effects of the SARS-CoV-2 infection and to the consequences of containment strategies, including physical distancing and disruptions to access to the healthcare system, especially for non-COVID-19 care (hereafter labelled as “the effect of the pandemic”).

First, PLWD are at a higher risk of SARS-CoV-2 infection since they may not be able to comply with the safeguard procedures and public health recommendations (Wang et al., 2020). They also are at a higher risk of severe COVID-19 disease complications and death as they often are more advanced in age and have multiple comorbidities (Center for Disease Control [CDC], 2020; Hacker Teper et al., 2019; Mondor et al., 2017; Sanità, 2020). A recent Canadian provincial report found that those with a dementia diagnosis were over-represented in SARS-CoV-2 cases and deaths (Institut national d'excellence en santé et en services sociaux, 2020). If scarcity of intensive care resources were to develop, they are at risk of being triaged away from life-saving healthcare (Smith et al., 2020).

These complications are exacerbated for PLWD in LTC, where the pandemic revealed existing inadequate organization of care (Bergman, 2020; Bolt et al., 2021; Brown et al., 2020; CDC, 2020; Kaasalainen, 2020; McGilton et al., 2020; Sanità, 2020). Almost 80% of all deaths in Canada have occurred in long-term care and seniors' homes (Walsh & Semeniuk, 2020), where around 70% of residents have dementia (Canadian Institute for Health Information, 2020b).

Second, PLWD, who require coordinated support from several health and social services (Borson & Chodosh, 2014; Canadian Academy of

Health Science, 2019; Hacker Teper et al., 2019), are experiencing unprecedented disruptions of their care. Access to health and social services has been limited due to the impossibility of face-to-face contact or due to catastrophic professional and volunteer shortages such as home care, day programs, LTC facilities, and community resources. Phone or virtual visits are being used by health care providers for ongoing care (Boivin et al., 2020), but these methods can pose special challenges to PLWD who frequently have hearing, visual, and functional impairments.

Third, specific infection measures implemented by different levels of health authorities and general public appeals to practice physical distancing prevent family and friends from visiting PLWD and disrupt daily routines (e.g., walks, outings), which puts them at risk of isolation (Cudjoe & Kotwal, 2020), neuropsychiatric symptoms of dementia (Boutoleau-Bretonnière et al., 2020; Canevelli et al., 2020), and mental health issues (Boutoleau-Bretonnière et al.). These factors may contribute to putting PLWD, especially in LTC, at increased risk of being prescribed antipsychotics and benzodiazepines, medications that are associated with potentially severe adverse events (Schwarz et al., 2012).

Fourth, care partners may be experiencing increased challenges, especially in the community, as formal care services are disrupted for their loved ones and themselves (Roach et al., 2020). Optimal dementia care relies on caring for the dyad: the PLWD and care partners (Borson & Chodosh, 2014). Lack of adequate support for care partners, who may now need to provide additional support to a PLWD, could put both within this dyad at risk.

Fifth, PLWD may not seek necessary care because they or their care partners fear of COVID-19 infection, which may result in acute or chronic conditions being sub-optimally managed, leading to increased need for health care services and risk of all-cause mortality.

Considering these daunting challenges, we leveraged our existing infrastructure, methods, and network, to ensure a timely response to these significant challenges. This project utilizes tools and methods already developed by the Alzheimer Society of Canada (ASC), the College of Family Physicians Canada (CFPC) as well as the Canadian

Consortium on Neurodegeneration in Aging (CCNA). The CCNA is a research network that includes more than 320 clinicians, including nurses and physicians, and researchers throughout Canada who aim to accelerate progress in research on dementia. Together, following a participatory approach that will engage PLWD, their care partners, and healthcare decision-makers and clinicians, we will measure and describe the consequences of the pandemic for PLWD living in the community and LTC on mortality, use of health care services and experiences of PLWD, care partners, and primary care physicians. We will follow this with a deliberative dialogue to co-develop evidence-based and actionable recommendations for clinicians, including nurses, physicians, and other healthcare workers, and decision-makers to tackle the current wave of the pandemic and prepare for subsequent waves.

1. RESEARCH OBJECTIVES

- 1.1. To measure the impact of the pandemic on health and social services use, mortality, and where possible, COVID-19 infection rate of PLWD both in the community and in LTC facilities compared to before the pandemic.
- 1.2. To understand PLWDs' and care partners' perceived needs, behaviours related to health service use and the experiences of PLWD, care partners, and physicians with health and social services.
- 1.3. To generate and disseminate evidence-based and actionable recommendations on effective strategies to address the current wave of the pandemic and prepare for subsequent waves.

METHODS

This study is framed according to the Andersen healthcare utilization model (Andersen et al., 2013) (herein referred to as the Andersen model), which links outcomes (i.e., mortality, use of health services) to predisposing and enabling factors (i.e., need, access to services, experiences, behaviours related to health service use, sex, gender, socioeconomic status (SES), rurality). We will use a convergent mixed-method design where qualitative and quantitative studies will

complement each other to examine the pandemic's impact on health service use by PLWD and care partners in Canada (O'Cathain et al., 2010; Pluye & Hong, 2014). This design is particularly suited to study complex phenomena such as dementia care, where multiple organizations are involved in responding to complex patient and care partner's needs (Vedel et al., 2019). A retrospective observational cohort quantitative study design using administrative databases (objective 1) and a qualitative study using questionnaires and interviews (objective 2) will be conducted in parallel (Figure 1). Following these two objectives, we will integrate the quantitative and qualitative results by conducting a deliberative dialogue workshop to develop and disseminate evidence-based recommendations (objective 3). This study will be conducted in four provinces (Quebec, Ontario, Alberta, Saskatchewan). Together, these four provinces represent more than three quarters of the Canadian population (Government of Canada, 2020; Government of Canada, 2018).

We have adopted a participatory research approach (Alzheimer Society of Canada, 2015; Bush et al., 2017; Jagosh et al., 2012) to create long-lasting system changes (Bush et al.; Jagosh et al.), where stakeholders contribute to all the key research processes, including setting objectives, interpretation and validation of findings, and recommendation development. Our participatory approach aims to engage PLWD and care partners, as well as health organization managers and decision-makers. We followed the SPIRIT checklist (SPIRIT Group, 2013) for writing this protocol and made sure that no relevant items were missed.

2.1. Objective 1. We will use a retrospective observational cohort study to estimate the impact of the pandemic across provinces and by setting of care in PLWD. We will compare health services use, mortality, and where possible, COVID-19 infection in a fixed cohort of PLWD at the start of the pandemic (March 1st through December 31, 2020) (exposed group) to those in PLWD during the same calendar periods in the preceding year (unexposed group) (See Figure 2). This design will enable an accurate estimation of the impact of the pandemic on PLWD, accounting for seasonality and expected natural decline of the population.

Figure 1

Overall study objectives and design

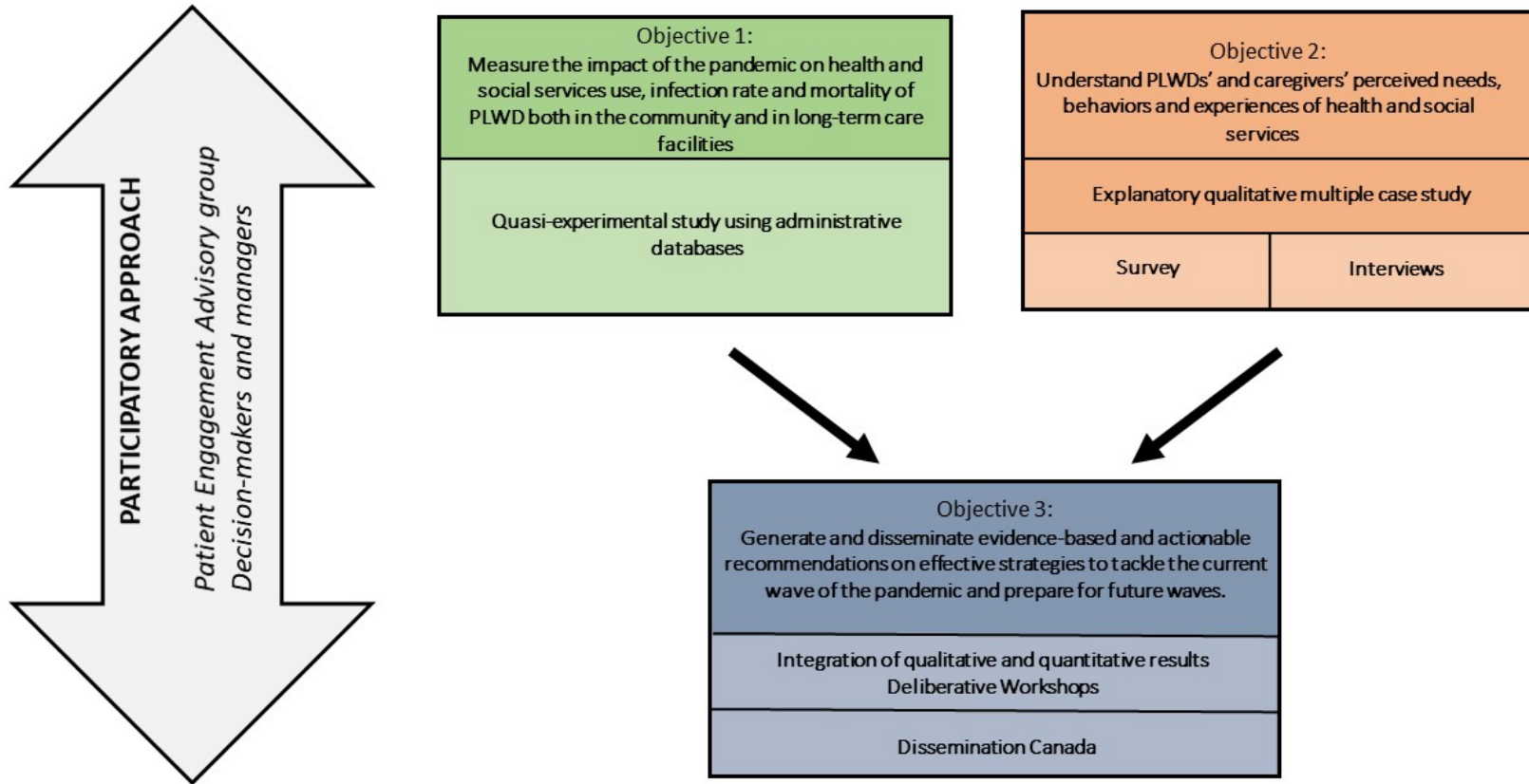
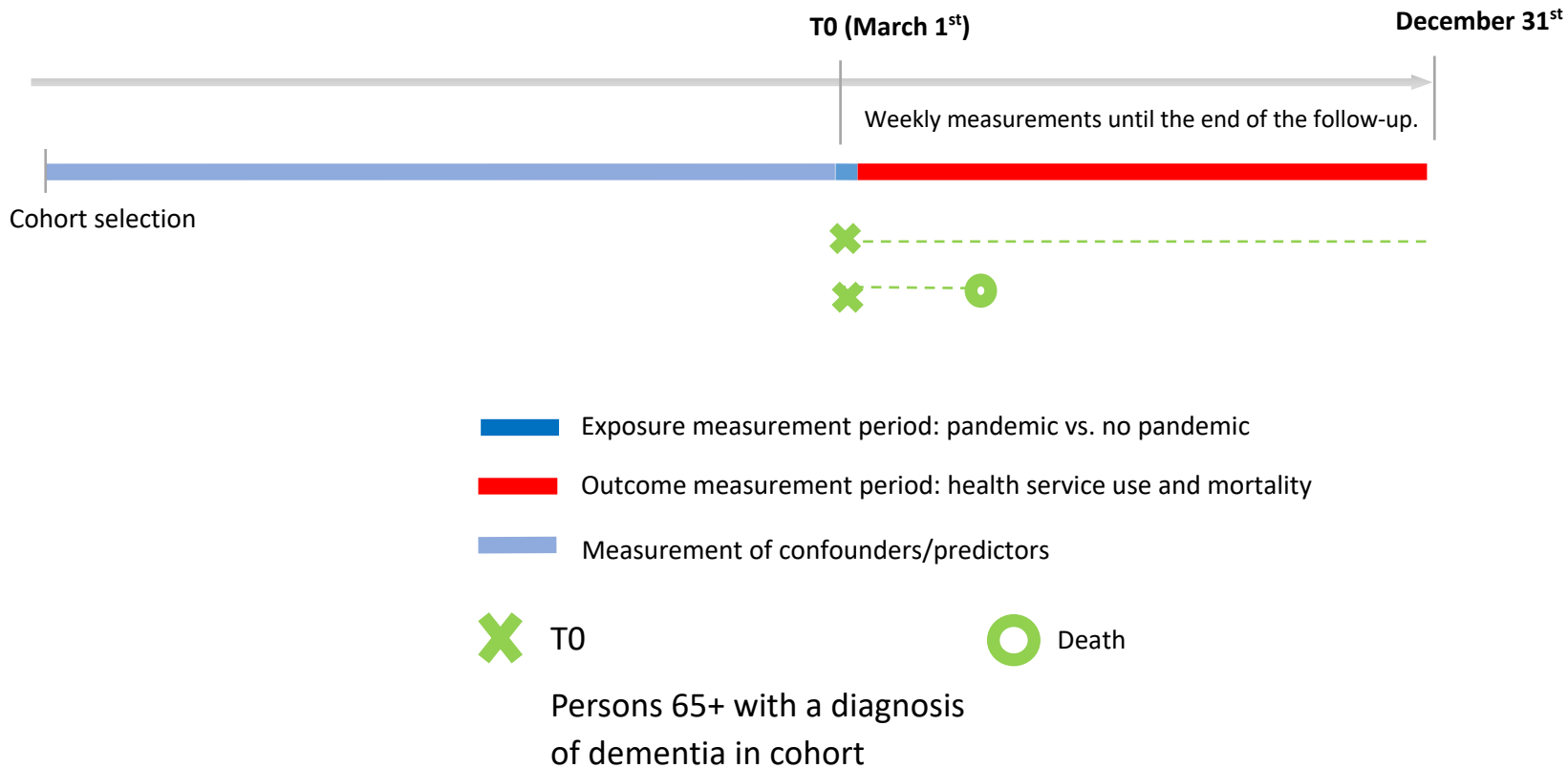


Figure 2

Objective 1 retrospective cohort study design



Fixed Cohort Design

Population: Persons aged 65+ with a prevalent diagnosis of dementia on March 1, 2020 (T0) and on the same day in 2019 (T0) as a historical control

Exposure: Presence of Pandemic

Outcome: Health services use and mortality measured weekly from March 1st to December 31st of pandemic year (2020) and historical control (2019)

Confounders/Predictors: Measured from T0 to 2 years prior

Stratification variables: Measured from T0 to T0-5 years

2.1.1. Data sources. We will analyze linked, population-based health administrative databases from the provinces of Quebec, Ontario, Alberta and Saskatchewan. These provinces offer a mix of urban and rural settings, as well as make up an estimated 76% of the Canadian population (Government of Canada, 2020; Government of Canada, 2018). Canada has a public, universal health system and, as such, these data account for the majority of services provided including emergency department (ED) visits, hospitalizations, physician visits, dispensed prescriptions (over/under age 65 years depending on the province), home care services, long-term care admission and mortality (Canadian Institute for Health Information, 2020a). The administrative health data is accessible approximately 3-8 months, depending on the database and the province, following service delivery. Some data sources are common to the provinces (Canadian Institute for Health Information, 2020a). We will request the databases through ICES (ON), *Institut de la statistique du Québec* (QC), Health Quality Council (SK), and Alberta Health Services (AB). All data within these administrative databases are anonymized and personal identifying information is removed. Data is only accessible by those approved and by the appropriate governing bodies where each database is held.

2.1.2. Population. Within each province, persons aged 65+ years, with a history of dementia on the first day of the exposed period (March 1, 2020) or unexposed period (March 1, 2019) will be eligible for inclusion in the cohorts. We will identify PLWD using a validated algorithm that was developed in Ontario at ICES and adopted by the Canadian Public Health Agency (Jaakkimainen et al., 2016). The research team already has experience with applying this algorithm in QC and ON.

2.1.3. Outcomes. As per the Andersen model, the main outcomes will be health services use and mortality. We will measure these outcomes from March 1st through December 31st of each year. We will select measures based on a framework of indicators our team previously developed and already operationalized in two provinces (Quebec and Ontario) (Sourial et al., 2021; Sourial et al., 2020) (see definitions in Table 1). Several of the

chosen outcomes are based on the feasibility of comparability between provinces. We will measure the outcomes throughout the follow-up period weekly beginning on the first day of each cohort selection period. In addition to the outcomes in Table 1, we will, where possible, measure COVID-19 infection rate, measure health service use and mortality due to COVID-19.

2.1.4. Covariates. As per the Andersen model, we will consider predisposing and enabling factors as covariates. We will consider the following potential confounders or predictors of the outcome in modelling the outcomes: age, sex, socioeconomic status, a proxy of rurality, region, available indicators of immigration status, comorbidity, stage or severity of disease, and time since diagnosis, the presence or absence of COVID-19, available neighbourhood contextual variables related to marginalization according to the 2016 Census, and attachment to an interdisciplinary primary care team (where possible).

2.1.5. Analysis. We will perform analyses in each province and stratify by whether an individual lived in LTC or the community, determined by a variable or an algorithm available in each province. We will also perform descriptive summary of the weekly events using Kaplan-Meier analysis for time to first event outcomes (e.g., LTC, mortality), and summarizing rates for other outcomes (e.g., visits to ED, hospital, ambulatory care). For each indicator, the denominator will be the persons still at risk at the beginning of each week (i.e., individuals alive, eligible for health care insurance coverage, and 65 years old or older at the beginning of each weekly follow-up). To allow a comparison of the impact of the pandemic throughout its different periods, we will aggregate and analyze the weekly data in three periods:

- Period 1: March – May (first wave)
- Period 2: June – September (plateau)
- Period 3: October – December (second wave)

We will apply the same periods to the exposed (i.e., pandemic) and unexposed (i.e., historical control) cohorts to examine the impact of the pandemic across these periods. We will compare the rates between provinces. To pool the provinces' rates, we plan to do a meta-analysis to analyze the overall trends of some comparable outcomes (Table 1).

Table 1*Operational definition for study indicators*

Indicator	Definition
Total visits to primary care physicians^a	Rate of visits to a primary care physician (in-person office or home, phone, or telemedicine) during the week among persons with dementia.
Total visits to specialists	Rate of visits to a specialist (in-person office or home, phone, or telemedicine) during the week among persons with dementia.
Visits to the emergency department	Rate of emergency department visits during the week among persons with dementia.
Potentially avoidable visits to the emergency department (ED)^b	Rate of potentially avoidable emergency department visits during the week among persons with dementia.
Hospitalizations	Rate of hospitalizations (non-elective) during the week among persons with dementia.
Intensive Care Unit (ICU) Hospitalizations	Rate of ICU hospitalizations during the week among persons with dementia.
Ambulatory care sensitive conditions (ACSC) hospitalization – General Population^b	Rate of hospitalizations during the week with a most responsible diagnosis of asthma, cardiac heart failure, Chronic Obstructive Pulmonary Disease (COPD), diabetes, hypertension, angina, seizures among persons with dementia.
ACSC hospitalization –Older Population^b	Rate of hospitalizations during the week with a most responsible diagnosis of asthma, cardiac heart failure, COPD, diabetes, hypertension, hypotension, dehydration, pneumonia, urinary tract infection, constipation, skin ulcers, weight loss, nutritional deficiency, adult failure to thrive, seizures.
Alternate Level of Care (ALC) hospitalization^b	Rate of hospitalizations during the week with ALC status among persons with dementia.
Readmissions to the hospital within 30 days following hospital discharge	Rate of hospital readmissions (non-elective) within 30 days of hospital discharge during the week among persons with dementia.
Prescribed benzodiazepines	Proportion of persons with dementia with at least one prescribed benzodiazepine during the week.
Prescribed antipsychotics	Proportion of persons with dementia with at least one prescribed antipsychotic during the week.
Use of home care^b	Rate of home care visits during the week (nurse or physician) among persons with dementia.
Admission to long-term care	Proportion of persons with dementia admitted to long-term care during the week.
Palliative Care^b	Rate of palliative care during the week among persons with dementia.
Mortality	Total number of persons deceased during the week among those persons with a diagnosis of dementia on the 1 st of the week.

^a Primary care visits include office, home, phone or virtual visits by a family physician or general practitioner. Maximum of one visit per patient per physician per day.

^b These indicators will be measured within each province and will not be comparable across provinces.

If the exposed and unexposed cohorts are not comparable at baseline, we will use propensity score-based inverse-probability weighting to increase the comparability of the exposed and unexposed (Austin, 2011) cohort and strengthen the causal interpretation of the results (Desai & Franklin, 2019; Hérnan & Robins, 2020). We will use the aforementioned covariates in the propensity score model. Comparability of the exposed and unexposed group in the weighted sample on measured confounders and predictors will be verified using descriptive (e.g., standardized mean differences) and graphical assessments. We will model the outcomes in the exposed and unexposed periods using generalized estimating equations to account for correlation across time periods in each group. Results will be presented as incident risk ratios, incident risk differences and numbers needed to treat to prevent one event. We will derive variance estimates using bootstrap methods (Austin, 2016) and perform a correction for multiple testing using the Bonferroni method. Finally, we will conduct a sensitivity analysis comparing the outcomes from the historical control (2019) and the preceding year (2018) to evaluate any differences that are not attributable to the pandemic.

2.2. Objective 2. We will conduct an explanatory qualitative multiple case study (Yin, 2009), where one case will be one province. We will combine data from two sources: survey (questionnaires) and semi-structured interviews.

2.2.1. Survey. We will use three questionnaires developed by the ASC and the CFPC in collaboration with patient and care partners: one for PLWD, one for care partners of PLWD, and one for family physicians. These questionnaires were pilot tested, and their face validity verified by the ASC and the CFPC for their respective questionnaires. These questionnaires assess the following domains: access to a family physician, experience with care and support received (e.g., experience with virtual visits) (30 closed and open-ended questions and five sociodemographic questions). The ASC and CFPC first distributed this survey in October 2020 nationally to PLWD and care partners, and to all Canadian family physicians. We expect 900 completed questionnaires (600 from PLWD and care partners,

300 from family physicians), with a targeted demographic approach to ensure representation of women, as well as Black, Indigenous, and Persons of Colour according to Statistics Canada data. The surveys were translated into five languages (English, French, Hindi, Simplified Chinese and Traditional Chinese) to facilitate this approach. We will conduct a descriptive analysis of the closed-ended questions and qualitative thematic analysis of the open-ended questions. We will then explore the associations between experiences of health and social services and gender, SES, rurality, and ethnicity. While the questions do not directly relate to the COVID-19 pandemic, participants are invited to share experiences that related to the pandemic in the instructions of the questionnaires.

2.2.2. Semi-structured interviews. As per the predisposing and enabling factors in the Andersen model, semi-structured interviews will explore care needs (e.g., unmet needs), behaviours related to health service use (e.g., how persons decide to go to ED or not) and experiences related to health and social service use by PLWD and care partners during the pandemic. In a pilot study with 20 care partners in Alberta, we identified the following themes: loss of personal support from family and friends, decreased access to healthcare (particularly day programs and home care services), and decline in mental and cognitive health of PLWD (Roach et al., 2020). We will interview a purposive sample of PLWD and care partners, including PLWD and care partners whose lived experiences speak to the diversity of the population (gender, rurality, sexual orientation, ethnicity, SES). An interview guide will be developed in close collaboration between persons with lived experience (persons living with dementia and care partners) and our team's qualitative research experts. We will recruit participants through local Alzheimer's Societies for people living in the community via email, newsletter and social media. We will recruit approximately 10 PLWD with the option to have their care partners present, we will conduct 10 interviews with care partners in each of the four participating provinces and conduct 1 hr semi-structured interviews with these 80 PLWD and care partners. We will also compensate the participants

of the interviews with a \$20 CAD gift card. We will develop an interview guide and test it in the field. We will conduct these interviews remotely by trained members of the research team in the language preferred by the interviewee (English or French) using the technology preferred by each PLWD and care partners (phone, Facetime, Skype, Zoom, etc.) (Janghorban et al., 2014; Wilkerson et al., 2014). The research team will contact all participants by phone or teleconference system to discuss the consent form. During this conversation, participants will have the opportunity to ask questions about the consent form and decide to participate or not in the research project, and if so, when they wish to participate. We will assess the PLWD's capacity to consent using an existing detailed script. For documentation purposes, the research team will record this process to document the agreement to participate on the study. Recording will be done upon the participants' agreement. We will then transcribe the interviews verbatim and entered it into NVivo12. One researcher from each province (four researchers total) will independently code a sample of the interview transcripts to develop a coding framework that they will then apply to the broader qualitative data set. In keeping with the iterative nature of qualitative data analysis, we may continually revise and modify the coding framework over the course of data analysis to account for emergent themes, as well as insights from researchers and collaborators. We will analyze the data using conventional qualitative content hybrid analysis using the Andersen model (Andersen et al., 2013) as a starting point and remaining open to new themes (Denzin & Lincoln, 2005). We will use several strategies to enhance rigour: sharing of non-identifiable sample of interview transcripts and summaries with our collaborators to obtain feedback, an audit trail of analytical decisions will be kept using 'memoing' in NVivo12, and reflexivity to account for personal biases.

2.2.3. Case Study Analysis. We will analyze the results from the survey and the interviews together using an explanatory qualitative multiple case study (Yin, 2009), where one case will be one province. The utilization of the case study method is appropriate when the phenomenon of interest is

embedded in its context (here, each province) and is multifactorial (Yin). We will conduct a within-case analysis followed by a cross-case analysis.

2.3. Objective 3. In order to generate and disseminate evidence-based and actionable recommendations on effective strategies to address the current wave of the pandemic and prepare for subsequent waves, we will first integrate the quantitative and qualitative results from objective 1 and 2, respectively grounded in the Andersen model (Andersen et al., 2013). To do so, we will build a meta-matrix as described in Miles and Huberman (1994). This will allow us to juxtapose outcomes and predisposing and enabling factors. It will help identify what factors we can act on to improve the outcomes. We will develop a series of infographics and data visualizations to clearly communicate these integrated results (Graham et al., 2006).

Then, we will conduct a virtual deliberative dialogue workshop, an appropriate method for bringing together multiple stakeholders to develop evidence-based recommendations for practice and policy (Boyko et al., 2012; Burchardt, 2014; Lavis et al., 2014; O'Brien et al., 2020). A deliberative dialogue is intended for diverse stakeholders to assess evidence. We will generate recommendations based on the lived and professional expertise of stakeholders (O'Brien et al.). Deliberative dialogue workshops are professionally moderated to encourage convergent and divergent views, and do not aim to establish a group consensus. Deliberations have been conducted successfully on diverse health issues including pediatric cancer care (Longo et al., 2021), primary care for women living with HIV (O'Brien et al.), medical assistance in dying (Boivin et al., 2019) and breast cancer screening (Abelson et al., 2018).

We will conduct the deliberative dialogue with 15 stakeholders from each of the participating provinces, for a total of 60 participants. The participating stakeholders will represent family and specialist physicians, nurses, social workers, managers, and PLWD and care partners. They will each be compensated with a \$20 CAD gift card. This workshop will be conducted in collaboration with the Canadian Foundation for Healthcare Improvement (CFHI), and the ASC. It will consist of

four steps: i) considering the evidence (see above infographics and data visualization), ii) deliberating together and separately within each province (using breakout rooms in Zoom), iii) sharing strategies and priorities across Canada, and iv) generating recommendations related to care of PLWD and care partners during a pandemic.

We will draw upon international resources to guide the facilitation of an online deliberation (Lupton, 2020; Tippin M et al., 2020; University College London, 2020). We will discuss tailored evidence-based recommendations for specific subpopulations (women, LGBTQ2+, low SES, racialized persons) and people living in rural regions, as their needs may differ (Cooper et al., 2015, 2017; Cooper et al., 2010; Cooper, 2018; Fredriksen Goldsen et al., 2019; Sivananthan et al., 2015; Sourial et al., 2020) from the majority and urban populations.

3. Participatory Research Approach. Our participatory approach is a community-based participatory approach, engaging PLWD and care partners; and an organizational participatory approach, engaging health organization managers and decision-makers.

3.1. Engagement of persons living with dementia and care partners. Increasing efforts are being put forward in research related to dementia to engage PLWD in a meaningful way (Bethell et al., 2018), which we adopted with the intentions to increase the credibility and legitimacy of our shared research project by benefiting from their unique lived experience, inform decision-making and identify gaps in healthcare services (Alzheimer Society of Canada, 2015). To this end, 16 PLWD and care partners were recruited through advertisements from the ASC, Federation of Quebec Alzheimer Societies, and the Engagement of People with Lived Experience of Dementia program from the CCNA. This group of 16 PLWD and care partners will provide insights to prioritize research questions from objective 1 and 2. They will also contribute to interpreting the results of objective 1 and 2. Finally, these 16 PLWD and care partners will enrich and actively participate in the deliberative dialogue of objective 3.

A distinct advisory group of PLWD and care partners previously reviewed and provided input on the surveys developed by the ASC.

3.2. Decision-makers and managers involvement. In addition, we are collaborating with various stakeholders representing decision-makers and managers from the ASC, Alzheimer's Societies, the Public Health Agency of Canada, Healthcare Excellence Canada (formerly known as the Canadian Foundation for Health Improvement), the CFPC, the Canadian Geriatrics Society, and Dementia Advocacy Canada to minimize the direct and indirect impacts of the current wave of the COVID-19 pandemic and prepare for subsequent waves. The decision-makers and managers have been involved in the research protocol development, tools development and distribution. They will be involved in the interpretation of objectives 1 and 2, as well as the deliberative dialogues of objective 3.

4. Knowledge transfer strategy. This research has the fundamental goal of producing evidence that will address current gaps on the impact of COVID-19 and facilitate the improvement of the design of effective and efficient care systems, service delivery mechanisms and public health policies to better support PLWD and care partners. Throughout this project, we will leverage our infrastructure, networks, and partners' existing communication platforms (website, Twitter accounts, ASC's newsletter, and CFPC and CFHI listservs) to continuously disseminate results as soon as they are available to ensure that this evidence may rapidly inform the response to the pandemic.

IMPACT AND CONCLUSION

The pandemic continues to be a challenge as global cases continue to rise (John Hopkins University, 2020). PLWD are increasingly vulnerable to the effects of the pandemic (Brown et al., 2020; Holder & Reddy, 2020). The pandemic has revealed existing gaps in care, for example, the lack of resources available to LTC and uncoordinated access to care. As frontline physicians, nurses and other healthcare professionals, managers, and policymakers continue to be overburdened by the additional stress of COVID-19 on the healthcare system, understanding the impact on and the experiences

of service use by PLWD and care partners is crucial to adapt our policies and practices. This knowledge can be used to design approaches that will mitigate disease spread. In addition, the disruption caused by the pandemic will likely reverberate through our healthcare systems in the long-term and in future health emergencies; this study can be used to address these disruptions in care. Our research aim is to contribute to improving the care for PLWD and care partners in a system persistently impacted by COVID-19 by: i) Accelerating the availability of high-quality and real-time evidence to support Canada's rapid response to the global pandemic to better prevent and manage COVID-19; ii) Improving the implementation of practices and policies and identifying the ones that are more promising to prevent and manage COVID-19 and similar health emergencies at the population levels; iii) Enabling Canadian engagement and coordination in national research and to better enable harmonized data collection, sharing of data, and quasi-experimental studies; iv) Providing evidence to inform clinical and health system management and the public health response within and across jurisdictions in Canada; v) Enhancing provincial and national collaborative efforts, to mitigate the rapid spread of COVID-19, related negative consequences, and prepare for future health emergencies.

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