

EXploring Patterns of use and Effects of adult Day programs to Improve Trajectories of continuing care (EXPEDITE): Protocol of a retrospective cohort study

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Abstract

Background: Adult day programs provide critical supports to older adults and their family/friend caregivers. High-quality care in the community for as long as possible, and minimizing facility-based continuing care are key priorities of older adults, their caregivers, and healthcare systems. While most older adults in need of care live in the community, about 10% of newly admitted care home residents have relatively low care needs that could be met in the community with the right supports. However, research on the effects of day programs is inconsistent. The methodological quality of studies is poor, and we especially lack robust, longitudinal research.

Objective: Our research objectives are to (1) compare patterns of day program use (including non-use) by province (Alberta, British Columbia, Manitoba), and time, (2) compare characteristics of older adults by day program use pattern (including non-use), province, and time, (3) assess effects of day programs on attendees, compared to a propensity score matched cohort of older non-attendees in the community.

Methods: In this population-based retrospective cohort study, we will use clinical and health administrative data of older adults (65+ years) who received publicly funded continuing care in the community in the Canadian provinces of Alberta, British Columbia, and Manitoba between January 01, 2012 and December 31, 2024. We will compare patterns of day program use between provinces and assess changes over time. We will then compare characteristics of older adults (e.g., age, sex, physical/cognitive disability, area-based deprivation indices, caregiver availability/distress) by pattern of day program use/ non-

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Results: This will be a 3-year study (July 1, 2024 – June 30, 2027). We received ethics approvals from the relevant ethics boards. Starting on July 1, 2024, we will work with the three provincial health systems on data access and linkage, and we expect data analyses to start in Early 2025.

Conclusions: This study will generate robust Canadian evidence on the effects of day programs on older adults and their caregivers. This will improve the quality of care provided to older adults in day programs, ultimately improving the quality of life of older adults and their caregivers. Clinical Trial: TBD

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Original Manuscript

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Conclusions: This study will generate robust Canadian evidence on the effects of day programs on older adults and their caregivers. This will improve the quality of care provided to older adults in day programs, ultimately improving the quality of life of older adults and their caregivers.

Trial Registration: ClinicalTrials.gov Identifier: NCT06440447

Keywords: Adult Day Care Centers; Aged; Program Evaluation; Cohort Studies; Routinely Collected Health Data

Introduction

Modern societies are struggling to meet the needs of an aging population [1–5]. The increasing prevalence of dementia [6–8] and co-morbid chronic conditions [9,10] lead to complex care needs [9,10] and to greater family/friend caregiver burden [11–14]. In response, health systems provide a range of ongoing care and supports to older adults and their caregivers – in Canada commonly referred to as continuing care [2,15]. Continuing care can be provided in an older adult's private home, in the community (e.g., an adult day program), or in a variety of congregate care settings including independent living, retirement homes, supportive/assisted living, or nursing homes (NHs) [16,17]. Governments have identified NHs as a major driver of public continuing care costs [16,18–20]. To mitigate pressures on public continuing care systems, and to meet aging in place preferences of older adults and their caregivers [21–23], reforms have implemented aging in place strategies. These strategies largely include (a) reserving NH care to those with the most complex care needs, and (b) improving access to an array of publicly funded continuing care options in the community [2].

Adult day programming is such a continuing care option to support aging in place [24–31]. Older adults in need of continuing care usually attend these programs for parts of the day, returning to their homes overnight (but overnight services are provided by some day programs). As the current literature illustrates [24–31], the number of days a person attends a day program can vary widely, depending on the program and health jurisdiction, from a couple of days/month to daily attendance. The amount of time an individual attends also varies, from a few hours/day to all-day, or sometimes during nights, and so do admission criteria, supports and services offered, and funding models.

Despite these variations, day programs have unique characteristics that set them apart from other continuing care options. Day programs employ care staff and admit people with a certain level of support needs [29,32]. This distinguishes them from senior or community centres [33] and creative arts programs [34], which are open to independent older adults, do not employ care staff, and are organized more informally. Unlike home care [35] or in-home respite [36], day programs serve groups of older adults in a setting external to the attendee's home [29,32], supporting social interactions and caregiver respite [31]. Unlike geriatric day hospitals, which provide medical, therapeutic, and rehabilitative care for a few weeks [37], day programs prioritize social and recreational activities, and they do so long-term (often for months or years) [29,32]. Day program services and supports usually include transportation; meals; recreational activities (e.g., playing games, musical activities, crafting, painting); socializing with other clients and day program staff; physical, cognitive and spiritual activities; social work counselling; and case management support. Personal, nursing, and medical care are often not provided, or only to a limited extent, depending on the on the program and health system.

Recent literature reviews [27–31,38] reveal a growing body of evidence that suggests day program attendance may be associated with attendees' improved mental health, cognition, loneliness, quality of life, perceived health, physical functioning, use of polypharmacy, and mortality. These reviews also suggest that attendance may be associated with older adults' delayed admissions to congregate care, reduced risk for hospitalization, and improved caregiver burden, caregivers' feelings of competence, mental health, and wellbeing. However, reviews point to inconsistent findings, methodological limitations, and substantial heterogeneity of included studies. For example, a Canadian one group pre-post study suggested that Geriatric Depression Scale scores decreased (fewer depressive symptoms) from 5.0 at admission to a day program to 3.3 at discharge ($P=0.007$).

A quasi-experimental study comparing depressive symptoms between day program attendees with dementia and non-attendees with dementia in the United States [39], found no group differences. However, on days of attendance, the proportion of attendees with depressive symptoms decreased over time (from 24% to 19%, $P < 0.02$). A Canadian randomized controlled trial [40] found no difference in depressive symptoms between day program attendees and wait-listed non-attendees.

Across the literature, four key knowledge gaps persist: (1) We generally know little about the characteristics of day program attendees and non-attendees, or about those with different patterns of use. (2) We lack longitudinal data on changes in the aforementioned outcomes. (3) Generally, the methodological quality of available studies is poor [31], and we lack robust, large-scale, longitudinal evidence of older adult day programs on day program attendees – especially those living with dementia. With few notable exceptions [41,42], we especially lack current research on Canadian day programs with most research originating from the US or Canadian studies often dating back several decades [24,25,43]. (4) Differential effects of day programs on persons with multiple, intersecting vulnerabilities, are poorly understood, despite inequity concerns [38,44–46]. Advanced age puts individuals at risk of ageism; physical and cognitive disabilities may expose them to ableism; the majority of older adults and their caregivers are women, often experiencing gender-inequities; and giving and receiving care are associated with substantial healthcare costs, disproportionately affecting those with low income [47]. Racism or transphobia/homophobia can further increase these pressures, severely affecting older adults and their caregivers [48,49].

Our study will address these knowledge gaps comprehensively, rigorously, and simultaneously. We will address the following three research objectives:

1. Explore patterns of day program use (e.g., variations in time to first attendance, monthly hours of attendance, ongoing vs interrupted attendance, total time of day program exposure), using latent class analyses (LCA), and compare the frequency of each latent use class between provinces and over time.
2. Compare older adults' demographic, social, and health characteristics (e.g., age, sex, physical/cognitive disability, area-based deprivation indices, caregiver availability/distress) by day program use/non-use class, province, and time.
3. Assess whether, compared to a propensity score matched control group of non-attendees, day program attendees enter care homes at later points in time, use emergency, acute, or primary care less frequently, experience less cognitive and physical decline, have better mental health, and less distressed caregivers. We will assess potential modification of these effects by day program use/non-use class, age, sex, and social determinants of health (e.g., area-based deprivation indices).

Methods

Study Design

Using an integrated knowledge translation (iKT) approach [50,51], we partnered with a cross-Canadian team of experts to design this population-based retrospective cohort study (ClinicalTrials.gov Identifier: NCT06440447) covering the Canadian provinces of Alberta, British Columbia, and Manitoba, and we will collaborate with our experts throughout the study. Experts include older adults (some with dementia), their caregivers, Alzheimer societies, caregiver organizations, day program staff and managers, and government and health system decision makers. They will provide intimate knowledge of day programs, and the experience of attending them or caring for an attendee, which will help us interpret and contextualize our findings. We will use de-identified clinical and health administrative data from each of the three provinces. Our study will

follow the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) [52], and the REporting of studies Conducted using Observational Routinely-collected health Data (RECORD) [53] guidelines. Provincial data policies require data to remain in each respective province, preventing linkage across provinces and analyses of all data in one place. Therefore, in-house data analysts with each provincial health system will carry out the analyses separately with shared protocols and programs.

Setting and Sample

Our study settings are community-based continuing care systems. Each province provides access to a range of publicly funded community-based continuing care services, including adult day programs [54–62]. Each provincial health system determines and enacts access criteria and provides services (directly or via contracted providers) [54–62]. Day program eligibility is assessed in each province, using comparable processes, criteria, and assessments (i.e., the Resident Assessment Instrument – Home Care, RAI-HC, a standardized, valid, reliable assessment tool [63]) [59,64,65]. To be eligible, attendees need to have some care dependency, but also the ability to cope to some extent with activities of daily living, ambulate/transfer with no or minimal assistance, be continent or independent in managing continence products, exhibit no or easily manageable responsive behaviours, and either be alone for extended periods, or have a caregiver who requires respite. Our study cohort will include all individuals aged 65 years or older with an initial RAI-HC assessment completed between January 1, 2012 and December 31, 2021. We will follow everyone until they either move into a care home, are lost to follow-up (e.g., because of death, moving out of province, loss of public insurance eligibility), or until December 31, 2024 (the end of the period covered by our data). That will allow for a care trajectory of at least 3 years (for those with an initial RAI-HC assessment in Dec 2021), enabling us to assess the number and characteristics of individuals with different day program use patterns, and compare them to those who were never exposed to a day program.

Sample Size Calculation

The yearly average number of completed RAI-HC assessments is ~20,000-30,000 in Alberta, ~34,000-39,000 in British Columbia, and ~10,000 in Manitoba [66]. About 50% of those assessed receive a re-assessment within 12 months and another 10%-30% receive a re-assessment after >15 months [67]. There are 89 publicly subsidized day programs in Alberta (~3,300 spaces/day), 95 in British Columbia (~1,500 spaces/day), and 70 in Manitoba (~1,000 spaces/day), for a total of 254 day programs with 5,800 spaces on any given day. Some day program users do not attend daily, but only one or a few days per week, so the number of unique attendees exceeds the number of spaces/day. This corresponds to >20,000 attendees/year (>200,000 within the study period), each with multiple assessments. Our study sample size will be large enough to detect small effects sizes. With Cox proportional hazard models, adjusted for covariates explaining an assumed 25% of effect variance ($\alpha=0.05$, power=0.8) [68], we require a total sample of 1,327 participants to detect a hazard ratio for admissions to care homes of 0.6 (as can be expected based on a similar Canadian study [41]) in favor of day program attendees. Similarly, Kelly [42] was able to detect significantly fewer emergency department visits and hospital admissions/days among 812 day program attendees compared to 812 propensity score matched to non-attendees. Our expected sample size will be considerably larger than for those previous studies, allowing for complex statistical modeling.

Data Sources

For each individual in our cohort, designated provincial health system analysts will link all records available within the study time frame from the following databases: (1) Regional continuing care registries, documenting when an individual starts/stops receiving any community-based continuing care, including day programs, how these services change over time, and when an individual is admitted to a care home. (2) Population registries for each participant's demographic data. (3) RAI-HC assessments [63], completed annually for people receiving long-term home care (60+ days), and to determine day program eligibility. The RAI-HC will provide data on older adults' medical conditions, functional dependence, pain, cognitive impairment, mood, and behavioural problems. It also includes information on a person's marital/partnership status, caregiver availability, whether that caregiver lives with the older adult, and caregiver distress. Additional caregiver characteristics are not included in the available provincial databases, posing a limitation to our quantitative analyses. However, a related prospective cohort study that we are conducting in Ontario will allow us to link comprehensive caregiver and older adult data, and we are currently conducting additional qualitative research that will illuminate how caregiver characteristics may affect day program use and outcomes. (4) Discharge Abstract Database (DAD) for information on all inpatient hospital stays, including diagnoses and length of stay. (5) National Ambulatory Care Report System (NACRS) for all emergency department visits and diagnoses. In British Columbia we will use the physician payment file in addition, since NACRS is not collected in all emergency departments.[69] (6) Pharmaceutical information on out-patient prescription medications filled through a community pharmacy and covered by provincial drug formulary. (7) Care provider claims data for health service claims submitted for payment by healthcare providers (e.g., general practitioners, nurse practitioners, geriatricians, geriatric psychiatrists, neurologists, therapists), to obtain information on general and specialist health services used by participants.

Study Variables

Exposure

Our exposure will be different patterns of day program use/non-use, based on information from the provincial continuing care registries, documenting the dates a person starts/stops attending a day program, days of attendance, and the duration of each visit. Day program use patterns will be determined, using LCAs (see statistical analyses section below) [70]. We will categorize three continuous variables as low, low-moderate, high-moderate, or high use, using sample distribution quartiles: (1) Time between first RAI-HC assessment and first attendance of a day program, (2) average number of hours of day program attendance (i.e., total number of hours spent in a day program divided by the number of times attended), and (3) total number of days a person attended a day program. LCAs will also include a categorical variable, indicating whether a person consistently attended a day program or whether there were longer periods (several weeks) of non-attendance. Non-use will be defined as no day program exposure at any time during a person's continuing care trajectory.

Study Outcomes

The data sources noted above enable us to examine a range of important study outcomes. Data on the time between a person's first RAI-HC assessment and **admission to a care home** will come from provincial continuing care registries. **Symptoms of depression** will be assessed using the validated RAI-HC Depression Rating Scale (DRS) [71], with scores ranging from 0-14 and a cut-point of 3 or higher representing clinically meaningful depressive symptoms [71,72]. We will capture **physical**

and cognitive decline, using validated RAI-HC scales [63]: the Activities of Daily Living Hierarchy (ADLh) scale [73] and the Cognitive Performance Scale (CPS) [74]. Both scales range from 0 (no impairment) to 6 (maximum impairment), and our outcomes will be dichotomous, indicating any increase (versus no change or a decrease) between the previous and follow up measurement in each of these scales. Using care practitioner claims data, we will generate rates of **different types of primary and specialist care use** (e.g., family physician, specialists, nursing practitioner, allied health providers). We will use the DAD and NACRS databases to generate **rates of emergency room registrations, hospital admissions, and days in hospital** (including alternative level of care) [42]. Rates will be stratified by day program use/non-use pattern.

Demographic, Social and Health Characteristics

These will include older adults' age, sex, marital/partnership status (population registries and RAI-HC), physical disability (ADLh score >3), and cognitive impairment (CPS score >3). Available data sets only include a binary variable on biological sex (male/female) and no non-binary information on gender identity. We will also include RAI-HC measures of caregiver availability (item G1e) and burden (items G2a-c). Finally, we will include four publicly available area-level measures from the Canadian Index of Multiple Deprivation [75,76]: residential instability (e.g., housing insecurity, overcrowding, frequent moves), economic dependency (high number of older adults, children <15 years, persons receiving government transfers), ethno-cultural composition (e.g., immigrants, racialized individuals), and situational vulnerability (e.g., Indigenous Peoples, dwellings needing major repairs, low education). Using Statistics Canada data, each measure is derived for 54,775 geographical dissemination areas, using 17 variables. Quintile-based ranks for each of the indices (1=least deprived to 5=most deprived) will be assigned to individuals based on their home's postal code [76].

Propensity Score Matching Variables

To compare outcomes between day program attendees and non-attendees, we will use propensity score matching [77] (for details see statistical analyses). Propensity scores aim to ensure a similar distribution of baseline variables among treatment (day program attendees) and control (non-attendees) – akin to what random assignment aims to accomplish in randomized trials [77]. Since we lack evidence on differences between day program attendees and non-attendees, our objective 2 analyses, will be key to informing the selection of the exact covariates that will form the propensity score. We will derive covariates for day program attendees from the RAI-HC day program eligibility assessment (index date). For each day program attendee, we will identify potential matches as non-attendees whose first RAI-HC assessment was completed within ± 3 months of the attendee's index date (i.e., admission to long-term home care at about the same time). This RAI-HC assessment will provide the relevant covariates to enable propensity score matching with day program attendees as of their index date.

Our **first set** of matching covariates will be RAI-HC variables used by health systems to determine day program eligibility [59,64,65]: physical functioning (ADLh scale), cognition (CPS), behavioural symptoms (Aggressive Behaviour Scale, ABS [78]), bladder/bowel continence (items I1, I3), availability of a caregiver (item G1e), and caregiver distress (items G2a-c). This will ensure that control participants are potentially eligible to a day program. Possible reasons for non-attendance include the lack of day program spaces, preference not to attend, inability to afford the required co-payments, or not receiving a day program referral. Our experts assure us that the pool of potential matches far exceeds that of attendees, supporting the feasibility of this study and underscoring the lack of day program spaces. This approach excludes individuals whose care needs are either too low

or too severe for day program eligibility, but it minimizes confounding by the matched variables and ensures comparable groups at baseline [79–81]. Finally, we will include a **second set** of matching covariates: health and social characteristics identified in objective 2 by which attendees and potentially eligible non-attendees differ and that overlap sufficiently between attendees and non-attendees (e.g., age, sex, type/duration of publicly funded community care received before the matching index date, deprivation indices).

Additional Covariates

Additional covariates for model adjustment will come from RAI-HC, DAD, NACRS, pharmaceutical, and claims records (e.g., geriatric syndromes, medical diagnoses, prescribed medications). We might also adjust for additional community care services (e.g., in-home respite, home care).

Statistical Analyses

Objective 1: Explore Patterns of Day Program Use

Using our day program cohort, we will conduct LCAs to determine the number of different day program use patterns, using the 4 variables described in the exposures section. LCAs are widely used to identify subgroups by clusters of characteristics (i.e., parameters of day program use) [70]. In collaboration with our experts and guided by relevant literature, we will pre-specify the expected number of classes. We will carry out LCAs separately in each province. We will run models with the pre-specified number of classes, and with 1, 2, and 3 more and fewer classes than the number pre-specified [70]. We will compare the fit between models, using bootstrap likelihood ratio tests [70], and select a final model that reflects the same number and types of classes in each province, balancing theoretical, conceptual, and statistical considerations. To assess temporal changes in the number of day program attendees within each use pattern, and differences between provinces, we will report and graphically plot the proportion (95% confidence interval, CI) of individuals within each latent class by quarter and province.

Objective 2: Compare Older Adults' Characteristics by Day Program Use, Province, Time

Using our full cohort of day program attendees and non-attendees, we will descriptively assess the distribution of sample characteristics over time and by province. In each province and quarter, we will report and plot graphically the proportion (95% CI) of individuals with each characteristic, stratified by day program use class vs non-use. Using general estimating equations (GEEs) [82], we will assess whether the number of persons with each characteristic has changed over time and whether characteristics are associated with older adults' day program use/non-use pattern. We will run a separate GEE model for each characteristic within each province, with the respective characteristic as individual-level outcome. We will run binary logistic regressions for dichotomous variables (e.g., sex) and ordinal regressions for categorical variables (e.g., residential instability quintile). Models will account for repeated measures within individuals and include the independent variables year of assessment (to assess change in social determinants over time), use/non-use class (to assess differences in social determinants by day program use), and an interaction between year and use/non-use (to assess how social determinants differed between use/non-use patterns by year). Using random effects mixed regression models, we will pool provincial effects statistically. Other pan-Canadian studies, such as the Canadian Network for Observational Drug Effect Studies [83], have successfully applied this approach and developed rigorous protocols to minimize bias and

maximize consistency of regional analyses.

Objective 3: Assess Effects of Day Programs

To create a propensity score, we will run a logistic regression for each province with day program attendance/non-attendance as the dependent variable and adding matching covariates. We will use one-to-one matching (one matched non-attendee for every attendee) [77]. We will use matching without replacement [84] and apply an optimal caliper matching algorithm [85]. As per best practice recommendations [86], we will use a caliper width of 0.2 of the standard deviation of the propensity score's logit. If this matching approach does not allow us to achieve a sufficient sample size, we will use propensity score quintiles for matching.

We will compare sample characteristics and study outcomes between attendees and non-attendees in every year and province, using bivariate statistical tests (e.g., χ^2 or Fisher's exact tests for categorical variables, t tests or ANOVAs for continuous variables, and their non-parametric equivalents if variables violate statistical assumptions). To assess the effect of day program exposure on time to care home admission, we will specify a multi-level time-to-event model with a health region-level random effect [87]. Health systems in each of the three provinces are divided into five health regions [88–90], and regional policies may cause clustering effects that our models must account for. Each model will include day program use/non-use class as independent variable and will be adjusted for time varying variables. These will include matching variables, if appropriate (i.e., in case of group differences in matching variables over time or due to missing data) [79–81], and, if needed, additional covariates (e.g., demographics, social determinants, medical/functional conditions, non-day program community care). Covariates that differ between attendees and non-attendees with a p value ≤ 0.15 in the bivariate analyses will be considered for inclusion. We will add covariates stepwise, one-by-one and remove those that cause collinearity issues or decrease model fit. As in objective 2, we will pool provincial effects statistically, using random effects mixed regression models.

Using GEEs and a similar approach as for the time-to-event models (including separate models in each province and statistical pooling of their effects), we will assess whether the other study outcomes differ by day program use/non-use pattern. Models will include each study outcome of interest as a dependent variable, day program use/non-use class and time of assessment as independent variables, and similar covariates (using the same stepwise approach) as the time-to-event models. Models will also include a random term to account for repeated measures within individuals. The choice of a link function will be informed by the nature of the variable, and theoretical and empirical considerations. For example, the number of hospital, emergency department, or physician visits has been shown to follow a zero-inflated negative binomial distribution, sometimes requiring an offset for the natural logarithm of person-time [91]. For continuous outcomes (e.g., days spent in hospitals), we will use an identity link function, and for dichotomous outcomes (e.g., presence/absence of depressive symptoms), we will use a logit link function. All models will apply multiple imputation in case of missing data, which we expect to be small based on our previous work with the administrative healthcare data sources used in this study.

Results

Funded by an endowed research chair, the Helen Carswell Chair in Dementia Care (July 1, 2022 – June 30, 2027), this will be a 3-year study (July 1, 2024 – June 30, 2027). We received ethics approvals from the York University Ethics Review Board, Human Participants Review Sub-

Committee (e2022-412) and from the University of Alberta Health Research Ethics Board – Health Panel (Pro00127850), and we are in the process of obtaining ethics approvals from the University of British Columbia Research Ethics Board, and from the University of Manitoba Health Research Ethics Board. Starting on July 1, 2024, we will work with the three provincial health systems on data access and linkage, and we expect data analyses to start in Early 2025.

Discussion

Older adults, caregivers, and health systems urgently need solutions to empower older adults to receive care at home for longer. There are few feasible solutions, but day programs are one of them. Despite the knowledge that day programs could fill an immense and costly care gap, we lack the research needed to inform policy and drive practice change to make day programs more available. This study will generate robust Canadian knowledge on the effects of day programs on outcomes that matter most to older adults, their caregivers, and health systems. We will identify essential elements of day programs, and how they can be improved. We will provide critical evidence for health systems to help them leverage the full potential of day programs to provide appropriate care, prevent inequities and mitigate the need for emergency, hospital, and congregate care. Ultimately, we will improve QoL of older adults (including those with dementia) and their caregivers, alleviate caregiver burden, and reduce social costs associated with health and wellbeing. Future studies will expand this research to additional provinces and territories.

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Conflicts of Interest

None declared.

Abbreviations

ABS	Aggressive Behaviors Scale
ADLh	Activities of Daily Living Hierarchy Scale
CI	Confidence Interval

CPS	Cognitive Performance Scale
DAD	Discharge Abstract Database
EXPEDITE	EXploring Patterns of use and Effects of adult Day programs to Improve Trajectories of continuing care
GEE	General Estimating Equation
iKT	integrated Knowledge Translation
LCA	Latent Class Analysis
NACRS	National Ambulatory Care Report System
NH	Nursing Home
RAI-HC	Resident Assessment Instrument – Home Care
RECORD	REporting of studies Conducted using Observational Routinely-collected health Data
STROBE	Strengthening the Reporting of Observational Studies in Epidemiology

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