

Editor's key points

- ▶ Over 2 years, three-quarters of the sample population experienced a transition but most experienced multiple transitions, including 12.1% who had 4 or more emergency department visits in that time.
- ▶ Compound transitions, such as emergency department to hospitalization to residential care admission, were common.
- ▶ Approximately one-quarter of the sample made no transitions (and did not die).

Older persons living with dementia and their use of acute care services over 2 years in Alberta

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Abstract

Objective To characterize transitions to acute and residential care and identify variables associated with specific transitions among community-based persons living with dementia (PLWD).

Design Retrospective cohort study using primary care electronic medical record data linked with health administrative data.

Setting Alberta.

Participants Adults aged 65 years or older living in the community who had been diagnosed with dementia and who saw a Canadian Primary Care Sentinel Surveillance Network contributor between January 1, 2013, and February 28, 2015.

Main outcome measures All emergency department visits, hospitalizations, residential care (supportive living and long-term care) admissions, and deaths within a 2-year follow-up period.

Results In total, 576 PLWD were identified who had a mean (SD) age of 80.4 (7.7) years; 55% were female. In 2 years, 423 (73.4%) had at least 1 transition and, of these, 111 (26.2%) had 6 or more. Emergency department visits, including multiple visits, were common (71.4% had ≥ 1 , 12.1% had ≥ 4). Of those hospitalized (43.8%), nearly all were admitted from the emergency department; the average (SD) length of stay was 23.6 (35.8) days, and 32.9% had at least 1 alternate level of care day. In total, 19.3% entered residential care, most admitted from hospital. Those admitted to hospital and those admitted to residential care were older and had greater historical health system use, including home care. One-quarter of the sample did not have any transitions (or die) during follow-up; they were typically younger and had limited historical health system use.

Conclusion Older PLWD experienced frequent, and frequently compound, transitions that have implications for them, their family members, and the health system. There was also a large proportion without transitions suggesting that appropriate supports enable PLWD to do well in their own communities. The identification of PLWD who are at risk of or who make frequent transitions may allow for more proactive implementation of community-based supports and smoother transitions to residential care.

Les personnes âgées atteintes de démence et leur utilisation des services de soins aigus sur 2 ans en Alberta

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Résumé

Objectif Établir les caractéristiques des transitions vers les soins aigus et en résidence, et cerner les variables associées à des transitions précises chez des personnes dans la communauté vivant avec une démence (PCVD).

Type d'étude Une étude rétrospective de cohortes à l'aide de données tirées de dossiers médicaux électroniques et reliées à des données administratives sur la santé.

Contexte L'Alberta.

Participants Les adultes âgés de 65 ans ou plus vivant dans la communauté qui avaient reçu un diagnostic de démence et qui avaient consulté un collaborateur du Réseau canadien de surveillance sentinelle en soins primaires entre le 1^{er} janvier 2013 et le 28 février 2015.

Principaux paramètres à l'étude L'ensemble des visites aux services d'urgence, des hospitalisations, des admissions en résidence de soins (vie assistée et soins de longue durée) et des décès, sur une période de suivi de 2 ans.

Résultats Au total, 576 PCVD ont été identifiées; leur âge moyen (ET) était de 80,4 ans (7,7) et 55 % étaient des femmes. En 2 ans, 423 (73,4 %) avaient vécu au moins 1 transition et, parmi elles, 111 (26,2 %) en avaient vécu 6 ou plus. Les visites aux services d'urgence, y compris les visites multiples, étaient communes (71,4 % en comptaient ≥ 1 , 12,1 % en comptaient ≥ 4). Parmi les PCVD hospitalisées (43,8 %), presque toutes avaient été admises à partir des services d'urgence. La durée moyenne (ET) du séjour se situait à 23,6 (35,8) jours et 32,9 % avaient passé au moins 1 jour dans un autre niveau de soins. Au total, 19,3 % ont été admises en résidence de soins, la plupart à partir de l'hôpital. Celles admises à l'hôpital et celles admises en soins résidentiels étaient plus âgées et avaient des antécédents d'utilisation du système de santé plus nombreux, y compris des soins à domicile. Le quart de l'échantillon n'avait eu aucune transition (ni de décès) durant le suivi; ces personnes étaient typiquement plus jeunes et avaient des antécédents moins nombreux d'utilisation du système de santé.

Conclusion Les PCVD plus âgées avaient vécu de fréquentes transitions, souvent à répétition, qui entraînaient des répercussions sur elles, les membres de leur famille et le système de santé. Il y avait aussi une forte proportion qui n'avait pas eu de transition, ce qui porte à croire que des soutiens appropriés permettent aux PCVD de bien vivre dans leur propre communauté. L'identification des PCVD qui sont plus à risque ou qui vivent plus de transitions pourrait permettre une mise en œuvre plus proactive des soutiens communautaires et des transitions plus en douceur vers les résidences de soins.

Points de repère du rédacteur

- Sur une période de 2 ans, les trois quarts de la population à l'étude ont vécu une transition, mais la plupart ont vécu de multiples transitions, y compris les 12,1% qui ont effectué au moins 4 visites aux services d'urgence durant cette période.
- Les séries de transitions, comme passer du service d'urgence à l'hospitalisation et à l'admission en résidence de soins, étaient fréquentes.
- Environ le quart de l'échantillon n'a pas vécu de transition (et n'est pas décédé).

Older persons living with dementia (PLWD) use more health services than those without dementia, but it is their nearly doubled use of acute care that raises concerns from quality, cost, and outcomes perspectives,^{1,2} and such frequent use may indicate insufficient support elsewhere in the health system. Once in hospital, PLWD are more susceptible to delirium, falls, poor symptom management, and other complications.³⁻⁵ Regardless of the reason for admission, hospitalization costs for PLWD are higher than for those without, and dementia is the diagnosis most associated with alternate level of care (ALC).^{6,7} Alternate level of care days, when patients no longer require hospital-level care but cannot be safely discharged, have health system consequences and are associated with deconditioning and readmissions.⁸⁻¹⁰

Fortinsky and Downs describe 6 transitions for PLWD from symptom recognition to end of life, 3 of which are characterized by a change in the physical setting (home to hospital; home to residential care; and residential care to hospital).¹¹ Studies have documented frequent movement between these settings but few look at multiple transitions.^{12,13} As the first and most frequent point of contact, primary care providers play a crucial role in supporting PLWD at each transition¹⁴; however, a number of barriers to providing optimal dementia care have been described, often relating to a lack of dementia-specific information.^{11,15,16} More detailed information on the use of community, residential, and acute care would help primary care providers better understand how and when their patients use these services and enable them to target groups with potential unmet needs to decrease acute system use. Our objectives were to characterize transitions to acute and residential care among PLWD, and to identify variables associated with specific transitions. We linked primary care electronic medical records (EMRs) with administrative data to capture use of services across the system.

— Methods —

Design and data

This was a retrospective cohort study. We obtained EMR data from the Canadian Primary Care Sentinel Surveillance Network (CPCSSN), which collects de-identified EMR data from primary care providers (known as *sentinels*) via regional networks across Canada. At the time of the study, 225 sentinels contributed EMR data to Alberta's regional CPCSSN networks (the Northern Alberta Primary Care Research Network and the Southern Alberta Primary Care Research Network). These data include patient demographic characteristics, diagnoses, and physician billing claims. Electronic medical record data were linked to Alberta's administrative data, located within Alberta Health Services' Enterprise Data Warehouse. The health administrative data included the Discharge Abstract Database

(to identify hospitalizations); National Ambulatory Care Reporting System (to identify emergency department [ED] visits); Alberta Continuing Care Information System (to identify home care use and admissions to supportive living [SL] and long-term care [LTC]); Pharmaceutical Information Network (to identify prescription medications); and the provincial registry (to identify deaths). Unique patient identifiers were used to link the EMRs and other databases. The EMR¹⁷⁻¹⁹ and administrative data are regularly used for research.^{8,20,21} This study was approved by the research ethics board of the University of Alberta in Edmonton.

Sample

We used e-mail and clinic visits to request approval for linkage from sentinels (**Figure 1**). We obtained EMR data for patients 65 years or older with a diagnosis of dementia and at least 1 visit with the participating sentinel between January 1, 2013, and February 28, 2015. Dementia was defined using CPCSSN's diagnostic algorithm, which has shown high sensitivity (96.8%) and specificity (98.1%) against medical charts.¹⁸

Of the 643 patients for whom we received EMR data, 67 were excluded because they lacked a linkage identifier, died before the index date, or were in residential care. The final sample consisted of 576 older PLWD.

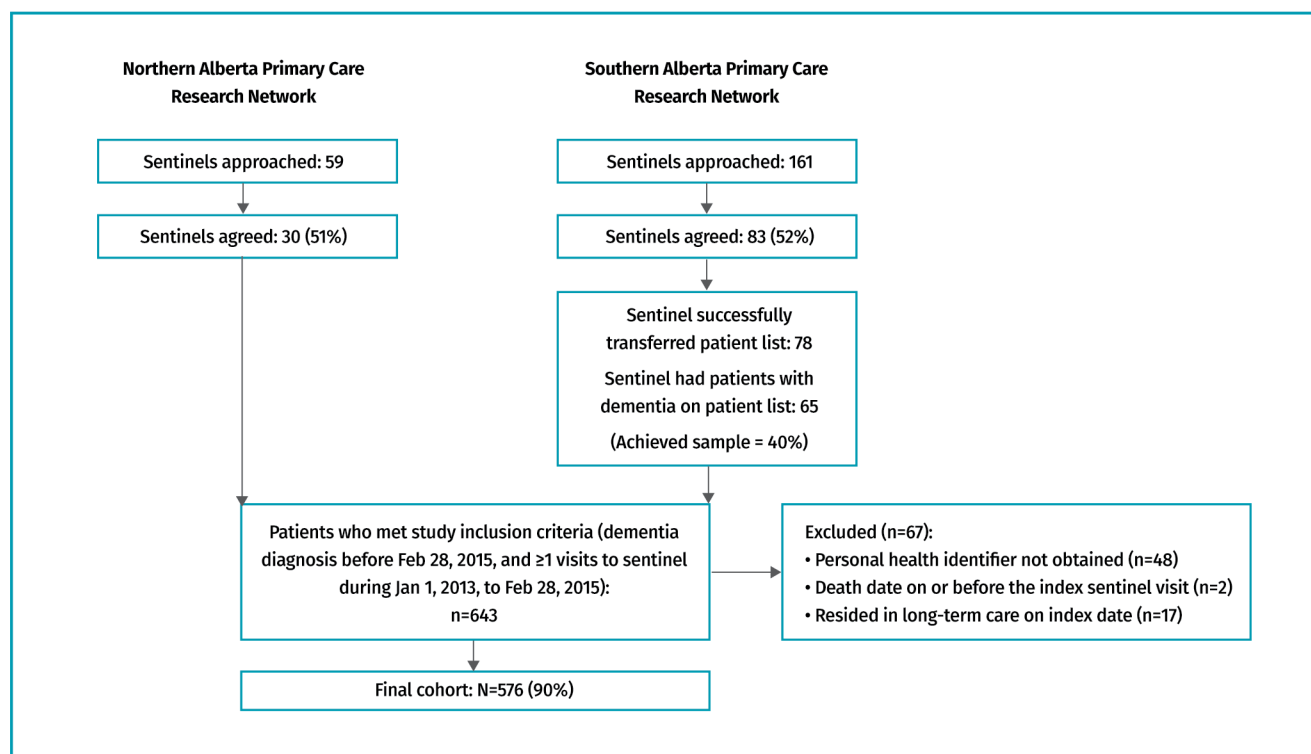
Transitions

We tracked all ED visits and hospitalizations from the index date until the first of SL, LTC admission, or death within a 2-year follow-up (February 28, 2017). Emergency department visits were characterized by discharge disposition. Hospitalizations were characterized by length of stay, ALC days, and discharge disposition.

We captured admissions into SL (comparable to assisted living elsewhere), and once an older PLWD was admitted to SL, we subsequently tracked LTC admissions and death. Once in LTC, we tracked death. We anticipated acute care use would change once in residential care. Those who had no transitions included individuals who had no ED visits or hospitalizations, were not admitted to SL or LTC, and did not die during the follow-up period.

Covariates

We included age, sex, location of residence (rural or urban by postal code), comorbid diagnoses, history of health service use, prescription medications, and socioeconomic status. Diagnoses identified by EMR were chronic obstructive pulmonary disease, depression, diabetes, epilepsy, hypertension, osteoarthritis, and Parkinson disease. Diagnoses identified by administrative data were cancer, chronic kidney disease, heart failure, liver disease, and prior stroke or transient ischemic attack. We generated a count of comorbid conditions. We captured the number of unique medications, antimentia medications, and medications with anticholinergic properties, as well as

Figure 1. Flowchart illustrating sample creation including sentinel agreement and patient inclusion criteria

Anticholinergic Risk Scale score^{22,23} in the year before the index date. For historical health service use, we captured the number of hospitalizations and ED visits in the year before the index date. We measured primary care provider continuity by estimating the proportion of primary care visits with the sentinel provider.²⁴ Continuity was categorized as high (>80% of visits with sentinel provider), medium (>50% to 80% with sentinel provider), low (≤50% with sentinel provider), or low primary care user (<3 visits to any primary care provider).²⁴ We estimated relative socioeconomic status using a material deprivation index (using local education, employment, and income) and a social deprivation index (using household and family structure) derived from local dissemination areas. Both indices range from most (first quintile) to least privileged (fifth quintile).²⁵

Analyses

We characterized the sample at index and counted all ED visits, hospitalizations, and SL and LTC admissions over the subsequent 2 years. For each transition, we described the discharge destination and sequence of transitions.

We conducted a series of regression models to identify characteristics associated with no transitions, hospitalization, and SL or LTC admission. In all cases, we modeled each variable separately and simultaneously, and conducted a reduced model that included only variables associated with the outcome or that acted as confounders. We managed death depending on its frequency and outcome. In the model of no transitions, death was grouped with other transitions (7 individuals

died without transitions). In the model on hospitalizations, death was grouped with hospitalization (14 people died without hospitalization). In the model of SL or LTC admission, we used a multinomial outcome (with neither admission nor death as the common reference).

Results

Of the 576 PLWD in our sample, the mean (SD) age was 80.4 (7.7) years, 55.0% were female, and 27.4% resided in rural areas. The most common comorbid conditions were hypertension (52.8%), osteoarthritis (37.8%), and depression (30.6%). Most (88.7%) had at least 1 comorbid condition, and 37.0% had 3 or more. The mean (SD) number of prescription medications was 8.5 (5.2) and 37.0% used 10 or more medications. Twenty percent used an anticholinergic medication, while 34.5% used medication with anticholinergic properties; 21.2% had an Anticholinergic Risk Scale score of 2 or more (Table 1).

In total, 73.4% experienced at least 1 transition during follow-up; of these, 26.2% experienced 6 or more. Another 25.3% made no transitions and did not die (Table 2). In Table 3, transitions in sequence and discharge locations are shown. Emergency department visits were consistently the most common transition, whether the first or the fifth transition; most ED visits ended with discharge home. There were 1364 ED visits made by 411 (71.4%) people (not shown in table); the mean (SD) number of visits was 3.3 (3.1) (not shown in table). Hospitalizations were the second most common

Table 1. Descriptive characteristics of sample at index date stratified by occurrence of any transition in 2-year follow-up period

CHARACTERISTIC	ANY TRANSITION OR DIED (n=430)	NO TRANSITIONS AND DID NOT DIE (n=146)	TOTAL (N=576)
Mean (SD) age, y	81.2 (7.5)	78.1 (7.7)	80.4 (7.7)
Age, y, n (%)			
• 65-69	40 (9.3)	26 (17.8)	66 (11.5)
• 70-74	45 (10.5)	23 (15.8)	68 (11.8)
• 75-79	69 (16.0)	33 (22.6)	102 (17.7)
• 80-84	123 (28.6)	33 (22.6)	156 (27.1)
• 85-89	94 (21.9)	21 (14.4)	115 (20.0)
• ≥90	59 (13.7)	10 (6.8)	69 (12.0)
Female sex, n (%)	234 (54.4)	83 (56.8)	317 (55.0)
Residence in a rural area, n (%)	122 (28.4)	36 (24.7)	158 (27.4)
Comorbid conditions at baseline, n (%)			
• COPD	65 (15.1)	12 (8.2)	77 (13.4)
• Depression	141 (32.8)	35 (24.0)	176 (30.6)
• Diabetes	92 (21.4)	39 (26.7)	131 (22.7)
• Epilepsy	11 (2.6)	2 (1.4)	13 (2.3)
• Hypertension	225 (52.3)	79 (54.1)	304 (52.8)
• Osteoarthritis	170 (39.5)	48 (32.9)	218 (37.8)
• Parkinson disease	19 (4.4)	1 (0.7)	20 (3.5)
• Heart failure	48 (11.2)	6 (4.1)	54 (9.4)
• Chronic kidney disease	76 (17.7)	9 (6.2)	85 (14.8)
• Liver disease	7 (1.6)	1 (0.7)	8 (1.4)
• Prior stroke or TIA	55 (12.8)	14 (9.6)	69 (12.0)
• Cancer	57 (13.3)	17 (11.6)	74 (12.8)
Comorbid conditions, n (%)			
• 0	44 (10.2)	21 (14.4)	65 (11.3)
• 1	100 (23.3)	44 (30.1)	144 (25.0)
• 2	111 (25.8)	43 (29.5)	154 (26.7)
• 3	97 (22.6)	25 (17.1)	122 (21.2)
• ≥4	78 (18.1)	13 (8.9)	91 (15.8)
Timing of dementia diagnosis, n (%)			
• On index date	140 (32.6)	53 (36.3)	193 (33.5)
• Before index date	290 (67.4)	93 (63.7)	383 (66.5)
Use of continuing care at baseline, n (%)			
• In home care	164 (38.1)	13 (8.9)	177 (30.7)
• In SL	23 (5.3)	2 (1.4)	25 (4.3)
Hospitalizations in prior year, n (%)			
• 0	300 (69.8)	129 (88.4)	429 (74.5)
• 1	98 (22.8)	14 (9.6)	112 (19.4)
• ≥2	32 (7.4)	3 (2.1)	35 (6.1)

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CHARACTERISTIC	ANY TRANSITION OR DIED (n=430)	NO TRANSITIONS AND DID NOT DIE (n=146)	TOTAL (N=576)
ED visits in prior year, n (%)			
• 0	173 (40.2)	98 (67.1)	271 (47.0)
• 1	109 (25.3)	34 (23.3)	143 (24.8)
• 2	55 (12.8)	6 (4.1)	61 (10.6)
• 3	41 (9.5)	4 (2.7)	45 (7.8)
• ≥4	52 (12.1)	4 (2.7)	56 (9.7)
Medication use in year before baseline			
• Mean (SD) unique medications, n	9.1 (5.4)	6.6 (4.2)	8.5 (5.2)
• ≥10 unique medications, n (%)	183 (42.6)	30 (20.5)	213 (37.0)
• Use of any anticholinergic medication, n (%)	89 (20.7)	26 (17.8)	115 (20.0)
• Use of medications with anticholinergic properties, n (%)	166 (38.6)	33 (22.6)	199 (34.5)
Anticholinergic Risk Scale score, n (%)			
• 0	264 (61.4)	113 (77.4)	377 (65.5)
• 1	64 (14.9)	13 (8.9)	77 (13.4)
• 2	33 (7.7)	5 (3.4)	38 (6.6)
• ≥3	69 (16.0)	15 (10.3)	84 (14.6)
PCP continuity in year before baseline, n (%)			
• High (>80%)	147 (34.2)	40 (27.4)	187 (32.5)
• Medium (>50% to ≤80%)	80 (18.6)	21 (14.4)	101 (17.5)
• Low (≤50%)	145 (33.7)	61 (41.8)	206 (35.8)
• Low primary care user (<3 visits)	58 (13.5)	24 (16.4)	82 (14.2)
Material deprivation quintiles, n (%)			
• 1 (most privileged)	85 (19.8)	36 (24.7)	121 (21.0)
• 2	60 (14.0)	23 (15.8)	83 (14.4)
• 3	57 (13.3)	15 (10.3)	72 (12.5)
• 4	48 (11.2)	13 (8.9)	61 (10.6)
• 5 (most deprived)	133 (30.9)	51 (34.9)	184 (31.9)
• Missing	47 (10.9)	8 (5.5)	55 (9.5)
Social deprivation quintiles, n (%)			
• 1 (most privileged)	33 (7.7)	23 (15.8)	56 (9.7)
• 2	45 (10.5)	7 (4.8)	52 (9.0)
• 3	104 (24.2)	37 (25.3)	141 (24.5)
• 4	108 (25.1)	40 (27.4)	148 (25.7)
• 5 (most deprived)	93 (21.6)	31 (21.2)	124 (21.5)
• Missing	47 (10.9)	8 (5.5)	55 (9.5)

COPD—chronic obstructive pulmonary disease, ED—emergency department, PCP—primary care provider, SL—supportive living, TIA—transient ischemic attack.

Table 2. Distribution of number of transitions over 2-year follow-up by persons living with dementia

NO. OF TRANSITIONS (N=576)	VALUE, n (%)
Any transition (ED visit, hospitalization, admission to designated SL or LTC)	423 (73.4)
• 1	62 (14.7)
• 2	90 (21.3)
• 3	73 (17.3)
• 4	52 (12.3)
• 5	35 (8.3)
• ≥6	111 (26.2)
Died but did not experience any transitions	7 (1.2)
No transitions and did not die	146 (25.3)

ED—emergency department, LTC—long-term care, SL—supportive living.

transition, with 405 admissions by 252 (43.8%) people (not shown in table). Among those hospitalized, the mean (SD) number of admissions was 1.6 (1.2) and mean length of stay was 23.6 (35.8) days; 83 (32.9%) had at least 1 ALC day and mean time in ALC was 40.9 (48.8) days (not shown in tables). Most patients were discharged home, although the proportion discharged to SL or LTC increased with later transitions. There were 111 (19.3%) admissions to SL or LTC, of which nearly all (94.6%) were from hospital. There were 53 deaths.

Compared with any transition or death, those who were more likely to have made no transitions were younger (adjusted odds ratio [aOR]=0.42, 95% CI 0.17 to 1.01), had limited historical ED use (aOR=0.62, 95% CI 0.38 to 1.02), and low primary care provider continuity (aOR=2.03, 95% CI 1.22 to 3.37); however, in all cases, 95% CIs were wide (Table 4). Older age (aOR=2.70, 95%

Table 3. Transition types and discharge locations in sequence over the 2-year follow-up period

TRANSITION TYPE	TRANSITION, n (%)					
	1ST* (n=423)	2ND* (n=361)	3RD* (n=271)	4TH* (n=198)	5TH* (n=146)	6TH AND ABOVE (N=481†)
Transition to ...						
• ED	403 (95.3)	213 (59.0)	180 (66.4)	137 (69.2)	95 (65.1)	336 (69.9)
• Hospital‡	6 (1.4)	133 (36.8)	62 (22.9)	44 (22.2)	40 (27.4)	120 (24.9)
• Supportive living	7 (1.7)	8 (2.2)	6 (2.2)	3 (1.5)	4 (2.7)	5 (1.0)
• Long-term care	7 (1.7)	7 (1.9)	23 (8.5)	14 (7.1)	7 (4.8)	20 (4.2)
If transition to the ED, discharged to ...						
• Hospital	132 (32.8)	60 (28.2)	43 (23.9)	40 (29.2)	24 (25.3)	91 (27.1)
• Home or community	271 (67.2)	153 (71.8)	137 (76.1)	97 (70.8)	71 (74.7)	245 (72.9)
• Death	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
If transition to hospital, discharged to ...						
• Home	1 (16.7)	52 (39.1)	14 (22.6)	12 (27.3)	10 (25.0)	40 (33.3)
• Home with support	3 (50.0)	46 (34.6)	25 (40.3)	20 (45.5)	20 (50.0)	33 (27.5)
• Supportive living	1 (16.7)	10 (7.5)	7 (11.3)	3 (6.8)	2 (5.0)	18 (15.0)
• Long-term care	1 (16.7)	18 (13.5)	10 (16.1)	7 (15.9)	6 (15.0)	22 (18.3)
• Death	0 (0.0)	7 (5.3)	6 (9.7)	2 (4.5)	2 (5.0)	7 (5.8)
If transition to supportive living ...						
• Subsequent transition to long-term care	0 (0.0)	1 (12.5)	1 (16.7)	0 (0.0)	0 (0.0)	1 (20.0)
• Death	0 (0.0)	0 (0.0)	1 (16.7)	0 (0.0)	0 (0.0)	0 (0.0)
If transition to long-term care ...						
• Death	2 (28.6)	3 (42.9)	5 (21.7)	4 (28.6)	1 (14.3)	7 (35.0)

ED—emergency department.

*These columns represent the number of people who made ≥1 to ≥5 transitions.

†Number of transitions, not people.

‡Hospital refers to inpatient admission.

Table 4. Characteristics associated with specific transition types over a 2-year follow-up period estimated using logistic regression

CHARACTERISTIC	NO TRANSITIONS (VS ANY TRANSITION OR DEATH)		HOSPITAL ADMISSION OR DEATH (VS NEITHER)		SUPPORTIVE LIVING OR LONG-TERM CARE ADMISSION (VS NO ADMISSION AND ALIVE)*	
	OR (95% CI)	AOR (95% CI)	OR (95% CI)	AOR (95% CI)	OR (95% CI)	AOR (95% CI)
Age, y						
• 65-69	1 (Ref)	1 (Ref)	1 (Ref)	1 (Ref)	1 (Ref)	1 (Ref)
• 70-74	0.84 (0.42 to 1.69)	0.84 (0.39 to 1.81)	1.03 (0.49 to 2.14)	0.89 (0.41 to 1.94)	1.19 (0.38 to 3.74)	1.31 (0.40 to 4.24)
• 75-79	0.74 (0.39 to 1.40)	0.81 (0.40 to 1.64)	1.48 (0.77 to 2.87)	1.20 (0.60 to 2.40)	1.66 (0.60 to 4.57)	1.32 (0.46 to 3.75)
• 80-84	0.48 (0.26 to 0.89)	0.51 (0.26 to 1.01)	2.42 (1.31 to 4.46)	1.93 (1.01 to 3.67)	2.78 (1.10 to 7.04)	2.09 (0.80 to 5.44)
• 85-89	0.36 (0.18 to 0.72)	0.43 (0.20 to 0.90)	2.69 (1.42 to 5.10)	2.03 (1.02 to 4.02)	3.91 (1.52 to 10.04)	2.59 (0.96 to 6.94)
• ≥90	0.29 (0.13 to 0.66)	0.42 (0.17 to 1.01)	3.80 (1.86 to 7.78)	2.70 (1.26 to 5.79)	4.92 (1.81 to 13.32)	3.20 (1.13 to 9.09)
Sex, male	1.01 (0.70 to 1.46)	1.08 (0.71 to 1.65)	1.10 (0.79 to 1.53)	1.13 (0.79 to 1.63)	0.99 (0.65 to 1.52)	1.22 (0.77 to 1.95)
Rural residence	0.76 (0.49 to 1.17)	NA	0.78 (0.54 to 1.13)	0.70 (0.46 to 1.07)	0.49 (0.29 to 0.84)	0.52 (0.29 to 0.93)
No. of comorbidities						
• 0	1 (Ref)	NA	1 (Ref)	NA	1 (Ref)	NA
• 1	0.98 (0.52 to 1.84)	NA	0.91 (0.49 to 1.67)	NA	1.12 (0.51 to 2.43)	NA
• 2	0.84 (0.45 to 1.57)	NA	1.58 (0.87 to 2.86)	NA	0.83 (0.37 to 1.84)	NA
• 3	0.60 (0.30 to 1.17)	NA	1.82 (0.98 to 3.38)	NA	1.58 (0.72 to 3.43)	NA
• ≥4	0.41 (0.19 to 0.88)	NA	2.61 (1.35 to 5.03)	NA	1.73 (0.77 to 3.91)	NA
In home care at baseline	0.20 (0.12 to 0.35)	0.30 (0.17 to 0.53)	3.27 (2.26 to 4.74)	2.21 (1.47 to 3.30)	3.67 (2.36 to 5.70)	2.91 (1.79 to 4.71)
≥10 unique medications	0.41 (0.27 to 0.62)	NA	2.46 (1.74 to 3.47)	2.01 (1.37 to 2.94)	1.25 (0.81 to 1.93)	NA
Antidementia medications	0.82 (0.51 to 1.32)	NA	1.54 (1.02 to 2.32)	NA	2.20 (1.36 to 3.56)	1.85 (1.10 to 3.13)
Hospitalization in prior year	0.35 (0.21 to 0.59)	NA	1.54 (1.02 to 2.32)	NA	1.06 (0.65 to 1.73)	NA
No. of ED visits in prior year						
• 0	1 (Ref)	1 (Ref)	1 (Ref)	1 (Ref)	1 (Ref)	1 (Ref)
• 1	0.53 (0.34 to 0.83)	0.62 (0.38 to 1.02)	1.47 (0.97 to 2.21)	1.16 (0.75 to 1.81)	1.32 (0.78 to 2.24)	0.99 (0.57 to 1.74)
• 2	0.18 (0.07 to 0.43)	0.22 (0.09 to 0.55)	3.26 (1.82 to 5.83)	2.54 (1.36 to 4.75)	2.82 (1.51 to 5.29)	2.38 (1.20 to 4.73)
• 3	0.20 (0.08 to 0.53)	0.29 (0.10 to 0.79)	1.95 (1.04 to 3.69)	1.32 (0.66 to 2.64)	0.94 (0.37 to 2.38)	0.74 (0.28 to 2.00)
• ≥4	0.13 (0.04 to 0.36)	0.16 (0.05 to 0.48)	3.08 (1.69 to 5.61)	2.18 (1.11 to 4.28)	0.97 (0.42 to 2.21)	0.80 (0.32 to 1.98)

Table 4 continued on page 122

Table 4 continued from page 121

CHARACTERISTIC	NO TRANSITIONS (VS ANY TRANSITION OR DEATH)		HOSPITAL ADMISSION OR DEATH (VS NEITHER)		SUPPORTIVE LIVING OR LONG-TERM CARE ADMISSION (VS NO ADMISSION AND ALIVE)*	
	OR (95% CI)	AOR (95% CI)	OR (95% CI)	AOR (95% CI)	OR (95% CI)	AOR (95% CI)
Anticholinergic Risk Scale score						
• 0	1 (Ref)	1 (Ref)	1 (Ref)	NA	1 (Ref)	NA
• 1	0.44 (0.23 to 0.82)	0.50 (0.25 to 1.01)	1.63 (0.99 to 2.66)	NA	1.33 (0.71 to 2.46)	NA
• 2	0.33 (0.12 to 0.85)	0.30 (0.11 to 0.84)	1.51 (0.77 to 2.94)	NA	2.69 (1.29 to 5.63)	NA
• ≥3	0.47 (0.26 to 0.85)	0.41 (0.21 to 0.79)	1.49 (0.93 to 2.40)	NA	1.18 (0.64 to 2.17)	NA
Provider continuity in year before baseline						
• High (>80%)	1 (Ref)	1 (Ref)	1 (Ref)	NA	1 (Ref)	NA
• Medium (>50% to ≤80%)	1.21 (0.68 to 2.14)	1.45 (0.77 to 2.73)	1.18 (0.72 to 1.91)	NA	1.31 (0.69 to 2.49)	NA
• Low (≤50%)	1.62 (1.02 to 2.56)	2.03 (1.22 to 3.37)	1.09 (0.73 to 1.62)	NA	1.32 (0.78 to 2.25)	NA
• Low primary care user (<3 visits)	1.61 (0.90 to 2.90)	1.33 (0.70 to 2.54)	0.81 (0.48 to 1.37)	NA	1.83 (0.96 to 3.50)	NA
Social deprivation quintiles						
• 1 (most privileged)	1 (Ref)	NA	1 (Ref)	NA	1 (Ref)	NA
• 2	0.26 (0.10 to 0.66)	NA	1.67 (0.78 to 3.59)	NA	2.03 (0.75 to 5.51)	NA
• 3	0.53 (0.28 to 1.01)	NA	0.97 (0.52 to 1.83)	NA	1.16 (0.48 to 2.80)	NA
• 4	0.55 (0.29 to 1.05)	NA	1.32 (0.71 to 2.47)	NA	1.60 (0.68 to 3.75)	NA
• 5 (most deprived)	0.52 (0.27 to 1.01)	NA	1.00 (0.53 to 1.90)	NA	1.00 (0.40 to 2.48)	NA
• Missing	0.32 (0.13 to 0.76)	NA	2.72 (1.26 to 5.87)	NA	3.52 (1.37 to 9.05)	NA

aOR—adjusted odds ratio, ED—emergency department, NA—not applicable, OR—odds ratio.

*Death treated as a separate outcome and full model results provided in appendix (available from CFPlus).

CI 1.26 to 5.79), having home care (aOR=2.21, 95% CI 1.47 to 3.30), taking 10 or more medications (aOR=2.01, 95% CI 1.37 to 2.94), and having a history of ED visits (aOR=2.18, 95% CI 1.11 to 4.28) were associated with hospitalization or death. Finally, older age (aOR=3.20, 95% CI 1.13 to 9.09), having home care (aOR=2.91, 95% CI 1.79 to 4.71), and use of anticholinergic medications (aOR=1.85, 95% CI 1.10 to 3.13) were associated with SL or LTC admission; the association with historical ED visits was less clear, likely due to small cell sizes. Similar

results were observed for death (Appendix, available at CFPlus*).

— Discussion —

We tracked older community-living PLWD over 2 years to describe their health service use. In that period, we

*The Appendix is available at <https://www.cfp.ca/>. Go to the full text of the article online and click on the CFPlus tab.

found that 73.4% experienced at least 1 transition but most experienced multiple transitions. Moreover, deaths were infrequent (9.2%) but one-fifth (19.3%) were admitted to residential care (SL or LTC).

Acute care use, especially ED visits, was common. Nearly everyone who had a transition visited the ED and most visited more than once. Studies of the general adult and LTC populations report approximately 4% make frequent ED visits,^{26,27} substantially lower than the 12.1% in our study. Given that everyone in our sample could be linked to a primary care provider, our findings raise questions about the extent to which providers were aware of the specific needs of PLWD or strategies to address them. More in-depth exploration of the precursors to ED use by community-living PLWD is needed.

Nearly half of our sample were hospitalized, most from the ED. Their average length of stay was more than 3 weeks and upward of 30% experienced ALC periods. Prolonged hospital stays with ALC days typically result from limited availability of suitable alternatives (SL, LTC, or other). In this study, one-fifth were admitted to SL or LTC, most from hospitals, despite robust policies designed to discourage this. These results suggest that additional strategies are still needed to reduce the frequency of SL and LTC admissions through hospitals. Further, they demonstrate the compound nature of transitions (eg, ED to hospitalization to SL or LTC) that get overlooked in studies of single transitions.

Surprisingly, 25.3% of our sample made no transitions. Although the small numbers limit interpretation, our results suggest that this group was younger, had fewer comorbid conditions, fewer medications, and less historical health system contact (which may partly explain the continuity of care findings). This group may represent those with milder dementia, who—because of limitations in measuring cognitive impairment in large databases—are often overlooked in reports of health system use by PLWD. Further research should determine what supports enable PLWD—at every stage—to remain out of acute and residential care, as well as the impact on family caregivers.

Limitations

This study was among the first to link CPCSSN data with administrative data and offers some lessons. As the data custodians in Alberta, sentinels were required to provide approval for linkage. Nearly half did not provide approval and we do not know why or how this affects the generalizability of our sample. Sentinels who did approve linkage were required to submit a mapping file for linkage, but this was a cumbersome request that resulted in data acquisition delays and further restrictions. These challenges illustrate the tension of balancing data custodianship and privacy against accessibility for health research. Other limitations include the small sample, which resulted in unstable estimates, and the

lack of data on functional impairment and caregiver needs, which have implications for health service use.

Conclusion

Older PLWD experience frequent transitions, from ED visits to prolonged hospital stays with nonacute needs to residential care, all with implications for them, their family members, and the health system. At the same time, a large proportion experienced no or minimal transitions, suggesting that appropriate supports can enable PLWD to thrive in their communities. The identification of PLWD at risk of or who make frequent transitions may allow for more proactive strategies to implement community-based supports and smoother transitions into residential care.

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Contributors

Drs Andrea Gruneir, Bonnie Dobbs, Jeff Bakal, Donna P. Manca, and Neil Drummond contributed to study conception and design. **Drs Gruneir, Dobbs, Adrian Wagg, Bakal, Manca, and Drummond** obtained funding. **Dr Gruneir, Erik Youngson, Dr Bakal, Dr Tyler Williamson, Kim Duerksen, Dr Stephanie Garies, Boglarka Soos, Brian Forst, Dr Bakal, Dr Manca, and Dr Drummond** contributed to data acquisition. **Dr Gruneir, Erik Youngson, Dr Williamson, Kim Duerksen, Dr Garies, Boglarka Soos, Brian Forst, Dr Manca, and Dr Drummond** contributed to data analysis and interpretation. **Dr Gruneir** wrote the first draft of the manuscript. **Erik Youngson, Dr Dobbs, Dr Wagg, Dr Williamson, Kim Duerksen, Dr Garies, Boglarka Soos, Brian Forst, Dr Bakal, Dr Manca, and Dr Drummond** provided critical input into manuscript development or revisions.

Competing interests

None declared

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