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A Scoping Review of Care Trajectories across Multiple Settings for Persons with Dementia

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Résumé

Les nombreux transferts entre les différents milieux de soins peuvent perturber les personnes âgées atteintes de démence et leurs proches aidants en provoquant des discontinuités dans les soins et des conséquences indésirables. Cette revue de la portée a été menée afin d'identifier et de classer les trajectoires de soins de personnes atteintes de démence dans différents milieux, et de comprendre la prévalence des transferts multiples et des facteurs qui y sont associés, aux niveaux individuel et organisationnel. La recherche a fait appel à trois bases de données, et ciblé les études revues par des pairs qui ont été publiées entre 2007 et 2017. Trente-trois articles ont été recensés selon ces critères. Nous avons observé 26 trajectoires de soins distinctes. Les trajectoires communes incluaient la réadmission à l'hôpital ou le transfert de l'hôpital vers les soins de longue durée. Les facteurs associés aux transitions concernaient principalement des caractéristiques démographiques et médicales. Les résultats mettent en évidence la nécessité d'investir dans l'amélioration de la performance des systèmes de soins communautaires en vue de diminuer le nombre de transferts. Des recherches plus approfondies sont recommandées afin de mieux comprendre les trajectoires de soins complexes et longitudinales, ainsi que celles de sous-populations atteintes de démence.

Abstract

Multiple transitions across care settings can be disruptive for older adults with dementia and their care partners, and can lead to fragmented care with adverse outcomes. This scoping review was conducted to identify and classify care trajectories across multiple settings for people with dementia, and to understand the prevalence of multiple transitions and associated factors at the individual and organizational levels. Searches of three databases, limited to peer-reviewed studies published between 2007 and 2017, provided 33 articles for inclusion. We identified 26 distinct care trajectories. Common trajectories involved hospital readmission or discharge from hospital to long-term care. Factors associated with transitions were identified mainly at the level of demographic and medical characteristics. Findings suggest a need for investing in stronger community-based systems of care that may reduce transitions. Further research is recommended to address knowledge gaps about complex and longitudinal care trajectories and trajectories experienced by sub-populations of people living with dementia.

Introduction

Dementia has been a pressing public health issue worldwide for several years. The number of people 65 years of age and older living with dementia in Canada nearly doubled from 218,000 in 2002 to 432,000 in 2016 (Public Health Agency of Canada, 2019b). More than 80,000 older adults in Canada are diagnosed in a single year (Public Health Agency of Canada, 2019b). Age is the greatest risk factor for dementia (Livingston et al., 2017), and although prevalence in Canada is less than 1% in the 65–69 year age group, it is 25% in the 85 and older age group (Canadian Institute for Health Information, 2018a). If the situation remains unchanged, the number of Canadians living with dementia will continue to increase as life expectancy improves and the share of older adults continues to grow.

The COVID-19 pandemic highlighted several challenges faced by older adults living with dementia in the community. Dementia increases the risk of exposure to the COVID-19 virus and to negative outcomes such as behavioural changes and delirium (Brown, Kumar, Rajji, Pollock, & Mulsant, 2020), thereby increasing the risk of hospitalization in this group (Alzheimer's Disease International, 2020). Unnecessary hospitalizations of people with dementia were already a concern in pre-pandemic Canada, with a hospitalization rate of 33 per 100 versus 20 per 100 people without dementia (Canadian Institute for Health Information, 2018a). Fear of exposure to the virus and social isolation in hospital prompted families to reconsider the risks and benefits of acute care (Alzheimer's Disease International, 2020). The pandemic also severely affected long-term care (LTC) homes in Canada, where 69% of residents live with dementia (Canadian Institute for Health Information, 2018a). In the first 3 months of the pandemic, more than 9,000 LTC staff were infected by the virus and 8 in 10 COVID-19 deaths across the country took place in LTC and retirement homes (Canadian Institute for Health Information, 2020).

The risk of admission to hospital or LTC for older adults with dementia therefore has serious consequences for this population and the larger Canadian health care system. A care transition refers to a physical move across locations that involves at least one overnight stay (Aaltonen, Rissanen, Forma, Raitanen, & Jylha, 2012) or consecutive days of care in different health care settings including home (Wang et al., 2017). Multiple care transitions are characterized by repeated or multiple moves between two or more care sites, or dynamic movement across multiple sites of care (Callahan et al., 2012, 2015). Care transitions across home, acute, and LTC settings by people living with dementia often result from increasingly complex care needs as function and health progressively decline (Alberta Health, Continuing Care, 2017; Fortinsky & Downs, 2014). In a United States study of older adults, the average number of care transitions between home, hospital, and LTC was two times higher among people with dementia than in those without dementia (Callahan et al., 2015). Furthermore, Callahan et al. (2015) found that 37% of older adults without dementia experienced no transitions during the observation period, compared with only 4% of individuals with dementia.

Previous reviews of care transitions experienced by persons with dementia have focused primarily on single and isolated moves between care settings (Afram, Verbeek, Bleijlevens, & Hamers, 2015; Dawson, Bowes, Kelly, Velzke, & Ward, 2015; Hirschman & Hodgson, 2018; Muller, Lautenschlager, Meyer, & Stephan, 2017; Ray, Ingram, & Cohen-Mansfield, 2015). Although multiple transitions have been the subject of two recent reviews, only hospital readmission has been considered (Ma, Bao, Dull, & Wu, 2019; Pickens, Naik, Catic, & Kunik, 2017).

A care trajectory is defined in this review as a pathway that consists of care transitions across multiple settings. Care trajectories merit attention as they may signal gaps in appropriate community-based care and support, contributing to negative health outcomes for people with dementia and their care partners. Episodes of transition expose individuals to possible medication error (Deeks, Cooper, Draper, Kurrle, & Gibson, 2016) and loss of critical information such as advance directives and care plans (Canadian Medical Protective Association, 2018). Care transitions cause disruptions in daily schedules and care continuity that can be particularly stressful and detrimental for those living with dementia, contributing to lower physical and psychological well-being (Ryman et al., 2019). Negative outcomes for care partners such as stress, depression, and anxiety have also been attributed to care

transitions, as well as disrupted self-care caused by a significant shift in focus to the individual with dementia (Sadak, Zdon, Ishado, Zaslavsky, & Borson, 2017). Emotional concerns and unmet needs for information and support among care partners have been shown to emerge throughout the care transition period; for example, before and after admission to LTC (Afram et al., 2015; Ray et al., 2015).

Although there is agreement that persons with dementia experience numerous transitions, there is less agreement on the standard classification of these transitions (Fortinsky & Downs, 2014). The purpose of this scoping review was to identify and classify care trajectories across multiple settings for people with dementia, and to gain an understanding of the prevalence of multiple transitions and related factors at the individual (demographic and medical) and organizational levels. The current review is intended to increase our knowledge of care trajectories in this population and to inform future research efforts by identifying key gaps in the literature and opportunities for research.

Methods

The review was guided by the Arksey and O'Malley (2005) five-stage scoping review methodology and additional steps for each stage as proposed by Levac, Colquhoun, and O'Brien (2010). Further, a review team met biweekly throughout the review process to consider decisions regarding the search strategy, study selection, and data extraction and analysis, as recommended by Levac et al. (2010).

Identifying the Research Question

This review aimed to answer the following research questions: What specific care trajectories involving multiple transitions are experienced by people with dementia in terms of care settings, and number and patterns of transitions? What is the prevalence of multiple transitions in this population? What are the factors associated with multiple transitions at the individual (demographic and medical) and organizational levels? For the purpose of this review, multiple transitions were defined as (1) two or more moves between at least three different care settings (e.g., home-hospital-LTC), (2) three or more moves between at least two different care settings that include home (e.g., home-hospital-home-hospital), or (3) two or more moves between two care settings that exclude home (e.g., LTC-hospital-LTC). We anticipated that the findings of this review would identify gaps in current knowledge and point to areas for future research.

Identifying Relevant Studies

A university health sciences librarian (E.W.) developed a comprehensive search strategy in consultation with the first two authors (Supplemental File). Computerized searches of three databases (MEDLINE*, Embase, and Cumulative Index to Nursing and Allied Health Literature [CINAHL]) were conducted in May, 2017. "Multiple transitions" and "compound transitions" are not commonly used terms, and for this reason our goal was to develop a broad search and manually remove "single transition" studies during study selection. The search was limited to peer-reviewed original research articles, in the English language, published between January 1, 2007 and May 3, 2017. Although the search was not limited to older adults, dementia is more common among older

populations, with people 65 years of age and older accounting for approximately 97% of cases (Canadian Institute for Health Information, 2018a). A 10-year period was chosen for the search, given the increased number of relevant studies in recent years, the pace at which recommendations are being addressed, and to balance the large number of records retrieved.

Study Selection

As shown in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram in Figure 1 (Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009), the search resulted in 16,704 records. This number was reduced to 10,870 after duplicates were removed. The records were exported to a reference program (Endnote) and a web-based systematic review program (DistillerSR), and further de-duplication reduced the number to 10,668 records.

In the first stage of study selection, four reviewers independently conducted title and abstract relevance screening based on initial inclusion/exclusion criteria. The first author (J.G.K.) screened all titles and abstracts, a second reviewer assessed half, and two additional reviewers each evaluated one quarter of the records. Inter-rater agreement was not calculated, as study selection was an iterative process involving ongoing deliberation among reviewers about the operationalization of "multiple transitions" as defined in the inclusion criteria (Table 1). After excluding 10,496 records, the second stage involved

reviewing the full text of 172 articles using a screening form developed by the first author, based on the final inclusion and exclusion criteria. The reviewers first tested the form with 19 articles, and revisions were made based on reviewer feedback. Three reviewers then each independently evaluated the full text of one third of the articles and the first author assessed all articles. Conflicts were resolved by discussion at both stages. The second author (D.G.M.) made the final decision on 5 records when consensus was not possible in the first stage, and consensus was reached between the first author and reviewers on all articles in the second stage. As shown in Figure 1, 33 studies were included in the current review after excluding 139 articles during the second screening stage.

Charting the Data

The first author extracted the data using a Microsoft Excel spreadsheet that was continually refined throughout the abstraction process to adequately capture key data. The following information was extracted from each study, where available: authors and year of publication; study country and setting, objectives, design, timeframe and study period, intervention, outcome measures, sample characteristics [age at baseline, sex, ethnicity, residence (e.g., rural, live at home or in long-term care), method of dementia identification such as clinical diagnosis, timing of dementia identification such as before first transition, proportion of patients with dementia and type of dementia, and
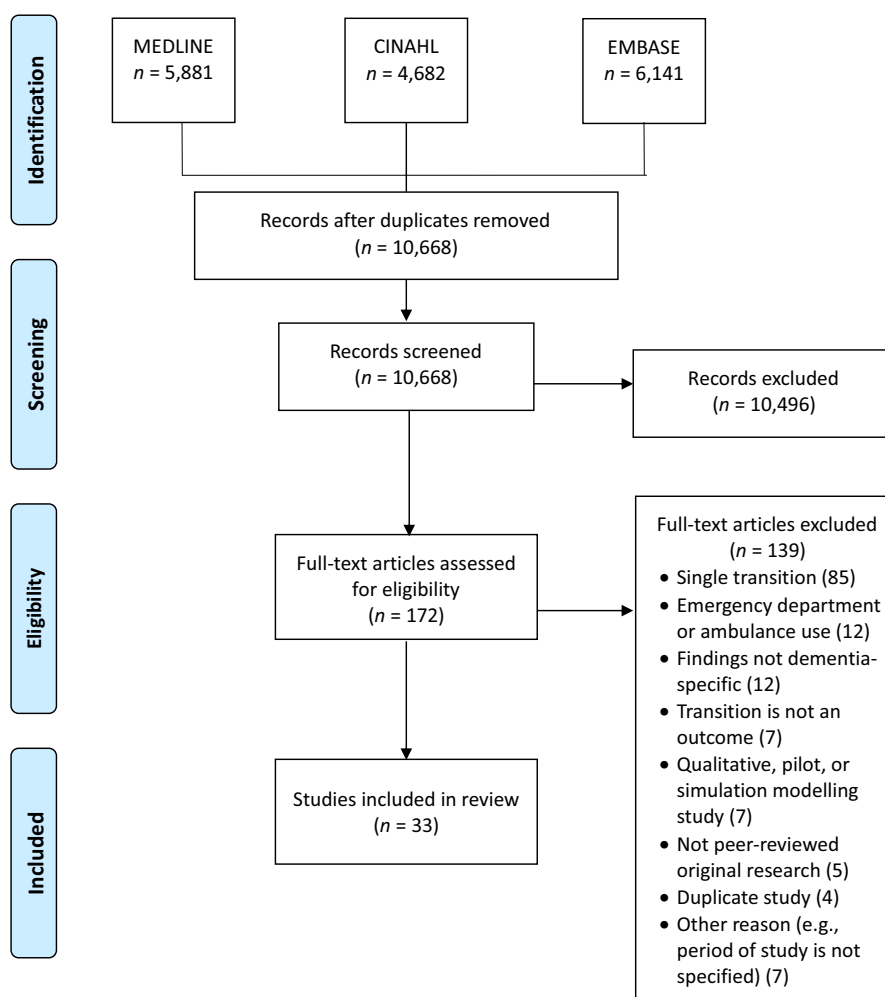

Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Flow Chart of Study Selection and Inclusion

Table 1. Study inclusion and exclusion criteria

Inclusion criteria
Study participants may reside in any setting at the start of the study.
Study participants must be individuals with dementia (and caregivers) only, or individuals with dementia (and caregivers) and controls wherein those with dementia are analyzed as a separate group.
Transitions between settings must be a study outcome, not a predictor.
Care settings must not include emergency departments, physician offices, or any care setting that does not imply an overnight stay.
Must examine multiple transitions, defined as any one of the following: • **At least 2 moves** between any 3 or more *different* settings (e.g., home-hospital-long-term care (LTC); LTC-home-hospital; hospital-LTC-palliative care) • **Including home, at least 3 moves** between 2 settings (e.g., home-hospital-home-hospital; home-LTC-home-LTC;) • **Excluding home, at least 2 moves** between 2 settings (e.g., LTC-hospital-LTC; hospital-LTC-hospital)
Exclusion criteria
Mixed-methods and qualitative studies Letters to the editor, opinion letters, commentaries, dissertations, reviews, study protocols, policy papers, reports, grey publications, and book chapters
Studies involving care settings that do not require an overnight stay (e.g., emergency department, physician office, home care)

proportion of patients with other medical conditions]; transitions as a primary focus (yes/no); and study conclusions, key implications and recommendations, and reported limitations. Data charting also included identifying and extracting care trajectories based on transition patterns that involved two moves, three moves, or four or more moves across settings, the prevalence of transitions, and factors associated with transitions at the individual (demographic and medical) and organizational levels. In addition, length of stay in hospital was documented where applicable. Some studies reported more than one trajectory, and data relevant to all routes were extracted where this was the case.

Collating, Summarizing, and Reporting the Results

The data extracted to Microsoft Excel were collated in a series of Microsoft Word tables (not included here) as an intermediate step, and study characteristics were organized in a numerical summary (Table 2). A framework of care trajectories was developed based on transition patterns extracted at the charting stage (Figure 2). This framework classifies trajectories based on starting location and other settings involved, number of transitions, and the pattern of movement across locations. For the purpose of this review, trajectories that began in an unspecified location or in hospital were considered to originate in location 'x'. We rationalized that hospitalization constitutes a temporary stay for individuals who have other permanent or long-stay living arrangements. In transitions that involved multiple unspecified locations, 'x' was counted as a single location.

The main findings in the narrative synthesis centre on the most commonly reported trajectories (as examined in three or more included studies), prevalence of transitions, and factors associated with transitions. Table 3 summarizes the relevant findings including all identified care trajectories, prevalence of transitions, associated factors, and key implications and recommendations.

Results

Study Characteristics

Characteristics of the 33 included studies are provided in Table 2. The majority of articles were published since 2015, and most studies were conducted in North America or Europe. Four studies

included an intervention (Boltz, Chippendale, Resnick, & Galvin, 2015; Cassel et al., 2016; Gustafsson et al., 2017; Noel, Kaluzynski, & Templeton, 2017). All of the studies included a mixed-sex sample, with females accounting for at least 60% of the dementia sample in three quarters of the studies.

Most studies assessed the effect of dementia on the use and outcomes of health services in general, of which transitions across care settings were only one component. Time frames considered in the studies ranged from less than 30 days to 5 years, with short time frames of less than 1 year examined most frequently. Few studies focused on time frames of 3 years or longer (Bucher, Dubuc, von Gunten, & Morin, 2016; Callahan et al., 2012; Chang et al., 2015; Rudolph et al., 2010; Seematter-Bagnoud, Martin, & Bula, 2012).

Individuals with dementia were identified on the basis of administrative data in the majority of studies. In these studies, diagnosis was recorded from the data either directly after the first transition had occurred (Daiello, Gardner, Epstein-Lubow, Butterfield, & Gravenstein, 2014; Draper, Karmel, Gibson, Peut, & Anderson, 2011; Harvey, Mitchell, Brodaty, Draper, & Close, 2016; Kasteridis et al., 2016; Oud, 2017; Zekry et al., 2009) or up to 1 year prior to the first transition (Davydow et al., 2014; Givens et al., 2013; Harvey et al., 2016; Mitchell et al., 2015; Mitchell, Harvey, Brodaty, Draper, & Close, 2016, 2017). Nevertheless, prevalent and incident cases were not differentiated in these studies, and the time since diagnosis was not provided. Only four studies, all based on administrative data, explicitly identified participants with incident (Callahan et al., 2012, 2015; Hsiao et al., 2015; Sivananthan & McGrail, 2016) or prevalent dementia (Callahan et al., 2012). Other studies relied mainly on clinical diagnoses or screening tests for identification purposes, often diagnosing or assessing participants either directly after the first transition (Boltz et al., 2015; Chang et al., 2015; Fogg, Meredith, Bridges, Gould, & Griffiths, 2017; Ono, Tamai, Takeuchi, & Tamai, 2011; Seematter-Bagnoud et al., 2012) or at study enrollment before the first transition occurred (Davydow et al., 2014; Fong et al., 2012; Noel et al., 2017; Rudolph et al., 2010; Voisin, Sourdet, Cantet, Andrieu, & Vellas, 2009). In these studies, it is possible that some participants were previously diagnosed with dementia. In studies with long observation periods in which dementia had been diagnosed at enrollment, it is also possible that some participants had been living with dementia for some time before their first transition.

Table 2. Study characteristics (*n* = 33)

	n
Continent of study	
North America	15
Europe	9
Australia	5
Asia	4
Date of publication	
2015-2017	19
2012-2014	9
2008-2011	5
Study design	
Retrospective cohort	18
Prospective cohort	6
Other[a]	9
Comparison/control group(s)	
No comparison/control group	17
One group without dementia	8
One group with dementia and another condition	1
Two or more groups, with or without dementia	7
Intervention study	4
Study focused primarily on transitions	14
Study time frame[b]	
30 days or less	12
3 months to less than 1 year	8
1 year to less than 2 years	12
2 years to less than 3 years	4
3 to 5 years	5
Unspecified	1
Method of dementia identification[c]	
Administrative data	
International Classification of Diseases (ICD) code	16
Prescription drug claim	2
Minimum Data Set (MDS) Data	1
Clinical diagnosis	8
Screening test	3
Medical record notes	2
Unspecified	3
Sample	
< 500	8
500-1,000	4
1,000-10,000	6
10,000-50,000	8
> 50,000	7
Minimum age (years) for study eligibility	
50-64	5

(Continued)

Table 2. *Continued*

	n
65-74	16
≥75	2
Unspecified	10
Female participants (% of dementia subsample)	
40-49.9	3
50-59.9	4
60-69.9	17
70-79.9	8
Unspecified	1
Rural participants	5

Note. [a]Other study designs included chart audit and caregiver survey; comparative repeated measures; cross-sectional; longitudinal cohort; observational cohort; randomized controlled trial; retrospective longitudinal observational; retrospective observational; and retrospective survey.
[b]Multiple time frames were included in 9 studies (Boltz et al., 2015; Callahan et al., 2012; Daiello et al., 2014; Draper et al., 2011; Gustafsson et al., 2017; Harvey et al., 2016; Kedia et al., 2017; Leung et al., 2013; Mitchell et al., 2016).
[c]Two studies used multiple methods of identification (Daiello et al., 2014; Mondor et al., 2017).

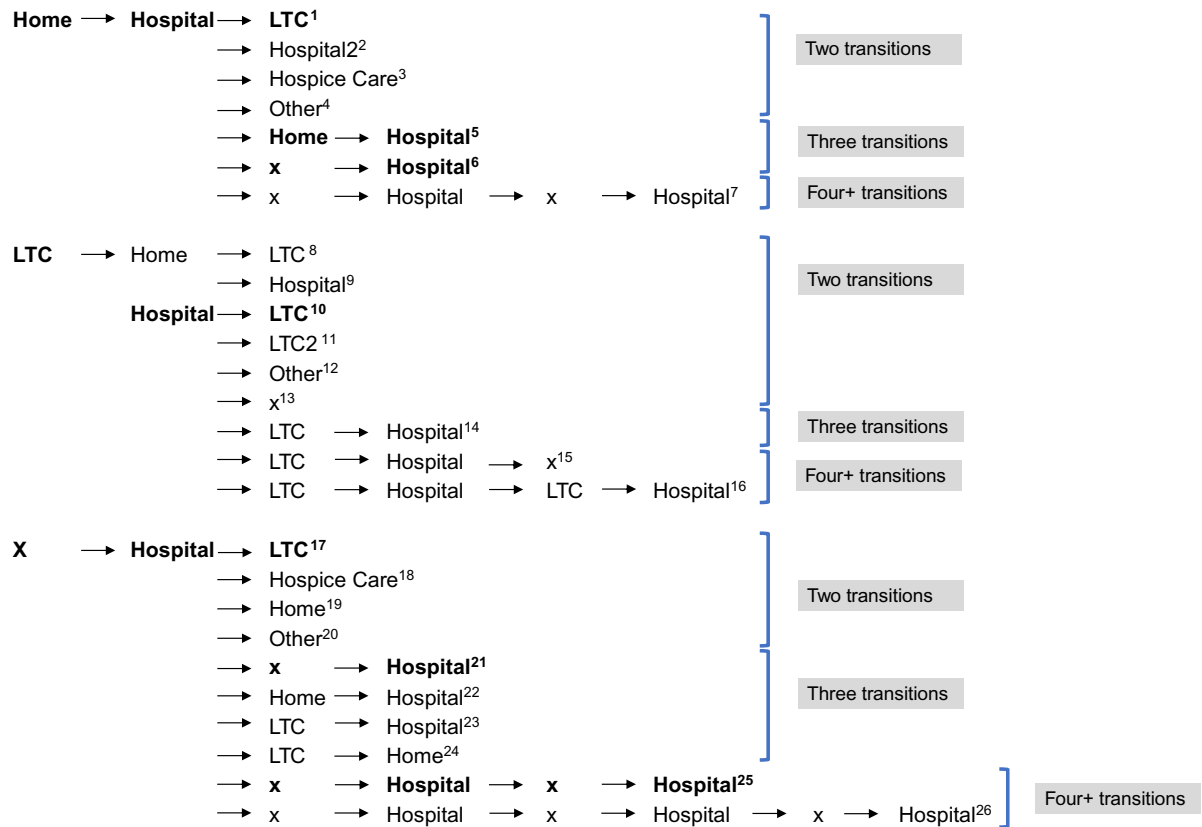## Prevalence of Transitions and Trajectories

We identified 26 distinct care trajectories experienced by individuals with dementia, based on the starting location of the trajectory and care settings involved, transition pattern, and number of transitions experienced (Figure 2 and Table 3). In most trajectories, the first transition involved hospitalization (*n* = 24); in two trajectories, the first transition was from LTC to home. Considering all 26 trajectories, the destination of the second transition was LTC in 10 trajectories, home or other location in 6, unspecified in 6, hospice care in 2 and hospital in 2 trajectories.

Described subsequently and organized by starting location are the seven most common trajectories, defined as those that were each examined in three or more of the included studies. These trajectories were examined in a total of 26 of the included studies. Included is the prevalence of each trajectory or the prevalence of specific transitions within the trajectories, as reported in the studies.

From home

The most common care trajectory beginning from home and involving multiple settings, as evaluated in nine studies, ended in transition to LTC after a hospitalization (*home-hospital-LTC*) (Boltz et al., 2015; Bucher et al., 2016; Fogg et al., 2017; Harvey et al., 2016; Kedia, Chavan, Boop, & Yu, 2017; Mitchell et al., 2016; Mondor et al., 2017; Ono et al., 2011; Zekry et al., 2009). Eight of the studies considered timeframes of 1–3.5 years, finding that 16.3 to 58.4 per cent of individuals with dementia admitted to hospital from home transitioned to LTC (Boltz et al., 2015; Bucher et al., 2016; Fogg et al., 2017; Kedia et al., 2017; Mitchell et al., 2016; Mondor et al., 2017; Ono et al., 2011; Zekry et al., 2009). One study found that 25.3 per cent of patients with dementia admitted to hospital with an injury in New South Wales were discharged to LTC; however, it did not specify the time frame (Harvey et al., 2016). Five studies included controls, and all found that hospitalized individuals with dementia were more likely to be discharged to LTC than people without dementia (16.3–35.9% vs. 3.5–8.6%) over

Home → Hospital → LTC[1]
                  → Hospital2[2]   ⎤ Two transitions
                  → Hospice Care[3]   ⎦
                  → Other[4]
                  → Home → Hospital[5]   ⎤ Three transitions
                  → x → Hospital[6]   ⎦
                  → x → Hospital → x → Hospital[7] ⎤ Four+ transitions

LTC → Home → LTC[8]
           → Hospital[9]   ⎤ Two transitions
Hospital → LTC[10]
         → LTC2[11]
         → Other[12]
         → x[13]   ⎦
         → LTC → Hospital[14]   ⎤ Three transitions
         → LTC → Hospital → x[15]   ⎤ Four+ transitions
         → LTC → Hospital → LTC → Hospital[16]   ⎦

X → Hospital → LTC[17]
             → Hospice Care[18]   ⎤
             → Home[19]   │ Two transitions
             → Other[20]   ⎦
             → x → Hospital[21]   ⎤
             → Home → Hospital[22]   │ Three transitions
             → LTC → Hospital[23]   │
             → LTC → Home[24]   ⎦
             → x → Hospital → x → Hospital[25]   ⎤ Four+ transitions
             → x → Hospital → x → Hospital → x → Hospital[26]

Figure 2. Twenty-Six Care Trajectories Identified in Included Studies (*n* = 33)

[1] Boltz et al., 2015; Bucher et al., 2016; Fogg, et al., 2017; Harvey et al., 2016; Kedia et al., 2017; Mitchell et al., 2016; Mondor et al., 2017; Ono et al., 2011; Zekry et al., 2009
[2] Ono et al., 2011
[3] Kedia et al., 2017
[4] Bucher et al., 2016
[5] Boltz et al., 2015; Cassel et al., 2016; Mondor et al., 2017; Ono et al., 2011; Sivananthan & McGrail, 2016
[6] Fong et al., 2012; Rudolph et al., 2010; Voisin, Sourdet, Cantet, Andrieu, & Vellas, 2009
[7] Voisin et al., 2009
[8] Callahan et al., 2012
[9] Callahan et al., 2012; Callahan et al., 2015
[10] Bucher et al., 2016; Callahan et al., 2012; Callahan et al., 2015
[11] Aaltonen et al., 2014; Givens et al., 2013
[12] Bucher et al., 2016
[13] Sivananthan & McGrail, 2016
[14] Leung, Kwan, & Chi, 2013; Sivananthan & McGrail, 2016
[15] Sivananthan & McGrail, 2016
[16] Aaltonen et al., 2014
[17] Bucher et al., 2016; Daiello, Gardner, Epstein-Lubow, Butterfield, & Gravenstein, 2014; Draper, Karmel, Gibson, Peut, & Anderson, 2011; Kasteridis et al., 2016; Seematter-Bagnoud, Martin, & Bula, 2012; Takacs, Ungvari, & Gazdag, 2015
[18] Oud et al., 2017
[19] Bucher et al., 2016
[20] Bucher et al., 2016
[21] Daiello et al., 2014; Davydow et al., 2014; Draper et al., 2011; Gustafsson et al., 2017; Harvey et al., 2015; Hsiao et al., 2015; Kedia et al., 2017; Mitchell et al., 2015, 2016, 2017; Noel et al., 2017
[22] Callahan et al., 2012, 2015
[23] Callahan et al., 2012, 2015
[24] Callahan et al., 2015
[25] Hsiao et al., 2015; Kedia et al., 2017; Teno et al., 2013
[26] Chang et al., 2015
x = unspecified location
Note: Bolded trajectories were examined in three or more studies. More than one trajectory was reported in 14 studies (Aaltonen et al., 2014; Boltz et al., 2015; Callahan et al., 2012, 2015; Daiello et al., 2014; Draper et al., 2011; Harvey et al., 2015; Hsiao et al., 2015; Kedia et al., 2017; Mitchell et al., 2016; Mondor et al., 2017; Ono et al., 2011; Sivananthan & McGrail, 2016; Voisin et al., 2009).

time frames of 1–2 years (Fogg et al., 2017; Harvey et al., 2016; Kedia et al., 2017; Mitchell et al., 2016; Zekry et al., 2009).

Reported in five articles, the second common trajectory that originated from home was characterized by hospitalization followed by re-hospitalization from home (*home-hospital-home-hospital*) (Boltz et al., 2015; Cassel et al., 2016; Mondor et al., 2017; Ono et al., 2011; Sivananthan & McGrail, 2016). Ono et al. (2011) reported in a retrospective cohort study conducted in one hospital

Table 3. Summary of included studies (*n* = 33)

Author, Date of Publication, Country, Study Design, Method of Identifying Individuals With Dementia	Sample, Minimum Age (Years), Mean Age (Years), Female %, Dementia %, Rural %	Trajectory Time Frame/ Study Period, Trajectory	Relevant Findings, Key Implications, and Recommendations
Aaltonen et al., 2014 Finland Retrospective cohort Dementia identification: ICD diagnosis code as cause of death	*n* = 18,912 residents in LTC nationwide (≥ 70 years of age) 13,159 nursing home mean age = 87.4 female = 75.6% 4,720 sheltered housing mean age = 86.8 female = 75.1% 1,033 LTC for people with dementia mean age = 86.6 female = 75.9% dementia = 100% (causes not specified) rural N/A	Last 90 days of life/ 6 years **Two transitions** • LTC1-hospital-LTC2 **Four or more transitions** • LTC-hospital-LTC-hospital-LTC-hospital	**Two transitions** • 0.3% of LTC residents were discharged from hospital to a different LTC facility (i.e., experienced a "type 2" care transition reflecting a lack of continuity in LTC facility) (90-day time frame) **Four or more transitions** • 5.5% of LTC residents were hospitalized more than two times (i.e., experienced "type 3" care transition) (90-day time frame) **Associated factors** **Two transitions** • After adjusting for age, sex, year of death, and co-morbidity, the odds of "type 2" care transitions from a LTC facility were lower among the oldest than among the youngest age group (AOR 0.35; 95% CI 0.15, 0.82), higher among residents of sheltered housing at baseline than among those in a traditional nursing home (AOR 13.69; 95% CI 6.36, 29.44) and higher among residents of specialized LTC for people with dementia at baseline than among those in a traditional nursing home (AOR 15.31; 95% CI 5.68, 41.30) **Four or more transitions** • After adjusting for age, sex, year of death, and co-morbidity, the odds of "type 3" care transitions were lower among the oldest than among the youngest age group (AOR 0.73; 95% CI 0.58, 0.90), lower among females than among males (AOR 0.74; 95% CI 0.64, 0.85), higher among residents of sheltered housing at baseline than among residents of traditional nursing home (AOR 4.08; 95% CI 3.56, 4.69), and higher among residents of specialized LTC for people with dementia at baseline than among residents of traditional nursing home (AOR 3.04; 95% CI 2.33, 3.97) **Key implications and recommendations** • Traditional nursing homes are likely better equipped than sheltered housing facilities to treat medical conditions that may arise at end of life and to avoid multiple hospitalizations • Specialized LTC facilities for individuals with dementia should be further regulated to ensure that they provide proper end-of-life care and prevent multiple hospitalizations
Boltz et al., 2015 United States Comparative repeated measures Dementia identification: Screening test at hospital admission (index hospitalization)	*n* = 86 patients in two hospitals (≥ 65 years of age) 44 intervention mean age = 83.8 ± 6.5 female = 52% 42 control mean age = 81.0 ± 8.5 female = 67% dementia = 100% (causes not specified) rural N/A	30 days, 18 months/18 months **Two transitions** • home-hospital-LTC **Three transitions** • home-hospital-home-hospital	**Two transitions** • There was no difference in the proportion of patients transferred from hospital to a nursing home between the intervention and control groups (27% vs. 26%; *p* = 0.56) (18-month time frame) **Three transitions** • The intervention group had a lower 30-day hospital readmission rate than the control group (7% vs. 24%; *p* = 0.02) **Intervention** • The Family-Centred Function Focused Care intervention (Fam-FCC) was adapted to be "dementia capable" and is implemented by a registered nurse over 10-15 hours/week. Components included environmental and policy assessment (baseline, 3 and 9 months), staff education (baseline, 2, 3, and 5 months), ongoing training and motivation of nursing staff (during 12 months), and family/patient education (during 12 months.). The control group received staff education. **Key implications and recommendations** • Reduced readmissions point with possible economic savings; however, further research such as a randomized controlled trial with a larger sample and longer intervention period is required

Table 3. *Continued*

Author, Date of Publication, Country, Study Design, Method of Identifying Individuals With Dementia	Sample, Minimum Age (Years), Mean Age (Years), Female %, Dementia %, Rural %	Trajectory Time Frame/ Study Period, Trajectory	Relevant Findings, Key Implications, and Recommendations
Bucher et al., 2016 Switzerland Retrospective cohort Dementia identification: Unspecified	*n* = 397 patients in three psychogeriatrics wards of one hospital (minimum age N/A) dementia = 100% (causes not specified) mean age = 81 female = 54.9% rural = N/A	3.5 years/3.5 years **Two transitions** • home-hospital-LTC • home-hospital-other ("other" included other psychiatric or acute care wards or death) • LTC-hospital-LTC • LTC-hospital-other • x-hospital-LTC • x-hospital-home • x-hospital-other	**Two transitions** • 91% of patients living in a nursing home before hospitalization were discharged to a nursing home, none were discharged home, and 9% were discharged to an "other" location (3.5-year time frame) • 58.4% of patients living at home before hospitalization were discharged to a nursing home, 29.3% were discharged home, and 12.6% were discharged to an "other" location (3.5-yr time frame) • 50% of patients living in an "other" location before hospitalization were discharged to a nursing home, 22.7% were discharged home, and 27.3% were discharged to an "other" location (3.5-year time frame) **Associated factors** • Patients discharged from hospital to a nursing home were older than those discharged home (mean age 82.03 years vs. 78.5; *p* = 0.002) • Widowed patients were more likely than married or other patients to be discharged from hospital to a nursing home (76.9% versus 54%, 67%; p = 0.001) • After controlling for age and sex, the odds of being discharged from hospital to home vs. to a nursing home were lower for males (OR 0.86; 95% CI 0.93, 0.99) **Key implications and recommendations** • Limited availability of home care and other home support services may contribute to discharge from hospital to nursing home • Longer hospital stays among patients discharged to a nursing home compared with other locations may be partly attributed to limited availability of space in nursing homes • Males may be less likely than females to be discharged from hospital to home if they do not have a spouse living at home • Future research should take into account the effect of family caregivers and hospital care on living arrangements after hospital discharge
Callahan et al., 2012 United States Prospective cohort Dementia identification: ICD diagnosis code at or prior to start of the study period (prevalent cases) or during the study period (*incident cases*)	*n* = 4,197 primary care patients in one city (minimum age N/A) 524 prevalent dementia mean age = 75.0 ± 6.7 female = 64.7% 999 incident dementia mean age = 73.4 ± 6.3 female = 71.5% 2,674 no dementia mean age = 70.7 ± 5.3 female = 68.6% rural N/A	30 days, 5.2 years (mean)/7 years **Two transitions** • LTC-hospital-LTC • LTC-home-hospital • LTC-home-LTC **Three transitions** • x-hospital-LTC-hospital • x-hospital-home (with services)-hospital • x-hospital-home (without services)-hospital	**Two transitions** • 20% of all individuals with prevalent or incident dementia were transferred from LTC to hospital and back to LTC, 14% were transferred from LTC to home and then to hospital, and 10% were transferred from LTC to home and back to LTC (5.2 year mean) **Three transitions** • The 30-day re-hospitalization rate among individuals with prevalent or incident dementia discharged to LTC was 25.3%, compared with 21.8% among those discharged home with services, and 20.2% among those discharged home without services **Key implications and recommendations** • Individuals with dementia should receive monitoring as they move across care settings, such as from LTC facilities back into their homes • To reduce re-hospitalizations, LTC facilities should be considered "transitory" sites in light of the frequency with which individuals with dementia transition between acute and LTC sites • Clarifying the goals of care is equally important as examining care transitions, regardless of whether care is provided at home, in hospital, or in LTC, given that much of the substance of the care for individuals with dementia is similar across the three sites

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Table 3. *Continued*

Author, Date of Publication, Country, Study Design, Method of Identifying Individuals With Dementia	Sample, Minimum Age (Years), Mean Age (Years), Female %, Dementia %, Rural %	Trajectory Time Frame/ Study Period, Trajectory	Relevant Findings, Key Implications, and Recommendations
Callahan et al., 2015 United States Longitudinal cohort Dementia identification: ICD (*first*) diagnosis code during transition timeframe	n = 16,186 persons nationwide with linked survey and Medicare claims records (age ≥ 65 years) 2,278 mild dementia mean age = 75.7 ± 8.9 female = 58.4% 1,169 moderate to severe dementia mean age = 79.5 ± 8.5 female = 69.6% 12,739 no dementia mean age = 68.2 ± 9.4 female = 55.4% rural N/A	12 months/10 years **Two transitions** • LTC-hospital-LTC • LTC-home-hospital (without services) • LTC-home-hospital (with services) **Three transitions** • x-hospital-home-hospital (without services) • x-hospital-LTC-hospital • x-hospital-LTC-home (without services) • x-hospital-home-hospital (with services)	**Two transitions** Compared with individuals without dementia: • Individuals with moderate/severe dementia (rate ratio 2.85; 95% CI 2.43, 3.33) or mild dementia (rate ratio 2.29; 95% CI 1.99, 2.64) were more likely to transition from LTC to hospital and back to LTC (12-month time frame) • Individuals with moderate/severe dementia (rate ratio 1.33; 95% CI 1.13, 1.55) were more likely to transition from LTC to home without services, and then to hospital (12-month time frame) • Individuals with moderate/severe dementia (rate ratio 0.65; 95% CI 0.43, 1.00) or mild dementia (rate ratio 1.14; CI 0.84, 1.55) were as likely to transition from LTC to home with services, and then to hospital (12-month time frame) **Three transitions** Compared to individuals without dementia: • Individuals with mild dementia (rate ratio 1.08; 95% CI 1.01, 1.15) were more likely to transition from hospital to home without services, and back to hospital (12-month time frame) • Individuals with moderate/severe dementia (rate ratio 6.19; 95% CI 5.13, 7.48) or mild dementia (rate ratio 4.54; 95% CI 3.88, 5.32) were more likely to transition from hospital to LTC and back to hospital (12-month time frame) • Individuals with moderate/severe dementia (rate ratio 2.68; 95% CI 2.34, 3.06) or mild dementia (rate ratio 2.10; 95% CI 1.88, 2.36) were more likely to transition from hospital to LTC and then to home without services (12-month time frame) • Individuals with mild dementia (rate ratio 1.37; 95% CI 1.12, 1.67) were more likely to transition from hospital to home with services, and back to hospital (12-month time frame) **Key implications and recommendations** • Individuals with dementia including those with moderate to severe dementia, experienced compound transitions among LTC, hospitals, and other settings such as home, to a greater degree than those without dementia • Hospitals are the "front door" to LTC for many individuals with dementia, and a growing 'network of care' exists that involves formal and informal providers and settings across home, hospitals, and long-term care facilities • Improve support for individuals with dementia in formal and informal settings
Cassel et al., 2016 United States Observational retrospective cohort Dementia identification: Unspecified	n = 1,443 community-based palliative care patients in one health system of one state (minimum age N/A) 368 intervention palliative care patients 92 (25%) dementia 37 (10.1%) cancer 65 (17.7%) COPD 174 (47.3%) heart failure mean age = 87 ± 5.9 female = 62% 1,075 control patients 276 (25.7%) dementia 111 (10.3%) cancer 189 (17.6%) COPD 499 (46.4%) heart failure mean age = 87 ± 6.1 female = 67% rural N/A	30 days/1.5 years **Three transitions** • home-hospital-home-hospital	**Three transitions** • Among individuals with dementia, the intervention group had a lower mean 30-day hospital readmission rate than the control group (11% vs. 35%; p = 0.01) **Intervention** • The Transitions program was delivered by a specialty palliative care team of physicians, nurses, spiritual care providers, and social workers. Components included in-home medical consultation, ongoing projection of survival, caregiver support, and advance health care planning delivered in acute (in-home visits) and maintenance phases (less frequent home visits plus phone calls). Patients received the intervention for less than 18 months for study purposes. The control group did not receive any components of the intervention. **Key implications and recommendations** • Earlier use of in-home palliative care may result in lower hospital use, lower health care costs, and positive patient outcomes (e.g., quality of life)

Table 3. *Continued*

Author, Date of Publication, Country, Study Design, Method of Identifying Individuals With Dementia	Sample, Minimum Age (Years), Mean Age (Years), Female %, Dementia %, Rural %	Trajectory Time Frame/ Study Period, Trajectory	Relevant Findings, Key Implications, and Recommendations
Chang et al., 2015 Taiwan Observational cohort Dementia identification: Clinical diagnosis at hospital admission (index hospitalization)	n = 203 patients admitted to one hospital (≥ 65 years of age) 48 (24%) AD mean age = 77.6 ± 6.0 female = 54.2% 96 (32.5%) VaD mean age = 78.0 ± 6.1 female = 44.8% 59 (29.1%) PRD mean age = 77.1 ± 5.9 female = 39% rural N/A	4 years /7 years **Four or more transitions** • x-hospital-x-hospital-x-hospital-x-hospital	**Four or more transitions** • 20.7% of all patients were admitted to hospital four or more times (4-year time frame) **Associated factors** • There was no difference among AD, VaD, and PRD patients in the risk of admission to hospital four or more times ($p > 0.05$) • Coronary artery disease ($p = 0.023$), pneumonia as etiology for last admission ($p < 0.0001$), urinary tract infection ($p < 0.0001$), and fall-related fracture ($p < 0.0001$) were associated with admission to hospital four or more times **Key implications and recommendations** • Hospital admissions for fall-related fractures among individuals with dementia must be addressed (e.g., physical training) and effective treatment plans implemented for patients with fall-related admissions to prevent readmission
Daiello et al., 2014 United States Retrospective cohort Dementia identification: ICD diagnosis code during index hospitalization; or prescription drug claim in 6 months prior to or following index hospitalization	n = 25,839 hospitalizations among 16,244 Medicare beneficiaries admitted to any hospital in one state (minimum age N/A) 3,908 hospitalizations with a dementia diagnosis mean age = 81 ± 11.7 female = 62.4% 21,931 hospitalizations without a dementia diagnosis mean age = 72.4 ± 14.5 female = 55% rural N/A	30 days, 12 months/12 months **Two transitions** • x-hospital-LTC **Three transitions** • x-hospital-x-hospital	**Two transitions** • Discharge from hospital to a skilled nursing facility was more frequent among patients with dementia than among patients without dementia (51.5% vs. 21.6% of hospitalizations; $p < 0.001$) (12-month time frame) **Three transitions** • 30-day hospital readmission was more likely among hospitalizations with a dementia diagnosis than without a dementia diagnosis (17.8% vs. 14.5% of hospitalizations; $p < 0.001$) • A diagnosis of dementia was associated with 30-day readmission to hospital (AOR 1.18; 95% CI 1.08, 1.29; $p < 0.001$), after controlling for demographics, comorbidities, and other factors **Key implications and recommendations** • The effect of dementia on readmission after hospital discharge should be further examined, particularly in diverse populations • Future research should investigate the effect of care transition programs on decreasing hospital readmission risk among individuals with mild dementia; e.g., self-management interventions
Davydow et al., 2014 United States Prospective cohort Dementia identification: Screening test at study enrollment or ICD diagnosis code in year prior to study enrollment	n = 7,031 community-based persons nationwide with linked survey and Medicare claims records (> 50 years of age) 842 depression alone mean age = 72.3 ± 9.2 female = 71% 945 cognitive impairment, no dementia (CIND) alone mean age = 77.3 ± 8.1 female = 55% 534 dementia alone mean age = 81.3 ± 8.3	30 days/10 years **Three transitions** • x-hospital-x-hospital	**Three transitions** • The proportion of the sample re-hospitalized within 30 days after initial hospitalization for pneumonia, congestive health failure, or myocardial infarction was not provided **Associated factors** • The odds of 30-day re-hospitalization were higher among individuals with co-morbid depression and dementia at baseline (compared with no neuropsychiatric disorder), after controlling for demographics, clinical (e.g., Charlson score over zero), and health-risk behavioral characteristics (e.g., alcohol use) at baseline (AOR 1.58; 95% CI 1.06, 2.35) **Key implications and recommendations** • Research is needed into adapting primary care-based interventions to acute

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Table 3. *Continued*

Author, Date of Publication, Country, Study Design, Method of Identifying Individuals With Dementia	Sample, Minimum Age (Years), Mean Age (Years), Female %, Dementia %, Rural %	Trajectory Time Frame/ Study Period, Trajectory	Relevant Findings, Key Implications, and Recommendations
	female = 62% 390 depression and CIND mean age = 75.7 ± 9.1 female = 67% 305 depression and dementia mean age = 80.2 ± 8.5 female = 66% 4,015 no depression, CIND, or dementia mean age = 73.8 ± 7.3 female = 54% rural N/A		settings to reduce depressive and behavioural symptoms in individuals with dementia, and to improve care transitions between hospital and primary care
Draper et al., 2011 Australia Retrospective cohort Dementia identification: ICD diagnosis code during index hospitalization	n = 253,000 patients admitted to one of 222 public hospitals in one state (≥ 50 years of age) 20,793 dementia 3,375 (16.2%) AD 1,483 (7.1%) VaD 2,096 (10.2%) other degenerative dementia 268 (1.3%) alcohol dementia 1,487 (7.2%) other dementia 12,084 (58.1%) unspecified dementia Unspecified n no dementia ≥ 85 years of age = 42.2% female = 60.1% rural N/A	3 months, 2 years/2 years **Two transitions** • x-hospital-LTC **Three transitions** • x-hospital-x-hospital	**Two transitions** • Compared with patients without dementia, those with dementia were less likely to be discharged from hospital to their usual residence than to a nursing home or other residence (transfer to usual residence OR 0.18; 95% CI 0.17, 0.18) (2-year time frame) **Three transitions** • Hospital readmissions within 3 months were more likely among individuals with dementia than among those without dementia (40% vs. 32%; *p* < 0.001) (3-month time frame) **Key implications and recommendations** • Younger individuals with dementia were possibly more likely to be readmitted than their counterparts without dementia given the behavioural and psychological symptoms associated with dementia in younger age groups, such as alcohol-related dementia
Fogg et al., 2017 England Retrospective observational Dementia identification: Screening test at hospital admission, including identification of individuals with pre-diagnosed dementia	n = 19,269 admissions to one hospital (≥ 75 years of age) 2,232 (11.6%) cognitive impairment (CI) and no known dementia mean age = 86.0 ± 5.9 female = 62% 3,818 (19.8%) diagnosed dementia mean age = 86.2 ± 5.6 female = 62.1% 13,219 (68.6%) no CI or dementia mean age = 83.4 ± 5.6 female = 45% rural N/A	22 months/22 months **Two transitions** • home-hospital-LTC	**Two transitions** • Patients with diagnosed dementia were more likely to be discharged from hospital to a nursing or residential home for the first time than patients with no cognitive impairment or dementia (16.3% vs. 3.5%; *p* < 0.001) (22-month time frame) **Key implications and recommendations** • Longer hospital stays among patients with diagnosed dementia may have been the result of medical complications during hospitalization and delay in transfer to LTC • Appropriate care in hospital for patients with dementia should include procedures for early discharge, mealtime support, bedside "forget-me-not" symbol, and wards with specially trained staff • Identify needs when discharging patients with dementia from hospital to ensure that necessary services are in place

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Table 3. *Continued*

Author, Date of Publication, Country, Study Design, Method of Identifying Individuals With Dementia	Sample, Minimum Age (Years), Mean Age (Years), Female %, Dementia %, Rural %	Trajectory Time Frame/ Study Period, Trajectory	Relevant Findings, Key Implications, and Recommendations
Fong et al., 2012 United States Prospective cohort Dementia identification: Clinical diagnosis at study enrollment	$n = 771$ community-based participants assessed at a specialized research centre ($\geq$ 65 years of age) 404 (52.3%) not hospitalized mean age = 75.9 $\pm$ 6.2 female = 59% 194 (25.2%) hospitalized with delirium mean age = 77.2 $\pm$ 6.3 female = 47% 173 (22.4) hospitalized without delirium mean age = 78.7 $\pm$ 6.2 female = 64% AD = 100% rural N/A	1 year/15 years **Three transitions** • home-hospital-x-hospital	**Three transitions** • 61% of patients with AD admitted to hospital were re-hospitalized (1-year time frame) • 67% of patients hospitalized with delirium compared with 55% patients hospitalized without delirium were re-hospitalized (significance test not provided) (1-year time frame) **Key implications and recommendations** • Examine the possibility of preventing delirium and hospitalization among individuals with AD
Givens et al., 2013 United States Retrospective cohort Dementia identification: Minimum data set (MDS) record of diagnosis at LTC admission	$n = 4,177$ residents from 3,292 nursing homes nationwide ($\geq$ 65 years of age) 2,557 skilled nursing facility mean age = 84.3 $\pm$ 7.0 female = 70.8% rural* = 24.7% 1,620 non- skilled nursing facility mean age = 84.3 $\pm$7.2 female = 72.2% rural* = 30.0% dementia = 100% (causes not specified) *not defined	6 months/6 years **Two transitions** • LTC1-hospital-LTC2	**Two transitions** • 61% of nursing home residents (LTC1) with advanced dementia admitted to hospital were subsequently admitted to a skilled nursing facility (LTC2) [6-month timeframe] **Associated factors** • Admission to a skilled nursing facility after hospitalization was independently associated with the insertion of a percutaneous endoscopic gastrostomy (PEG) tube during hospitalization (AOR 2.3; 95% CI 1.9, 2.9), better functional status (AOR 1.2; 95% CI 1.1, 1.4), diabetes mellitus (AOR .85; 95% CI 0.73, 0.99), and characteristics of the first nursing home including more than 100 beds (AOR 1.3; 95% CI 1.1, 1.5), part of a chain (AOR 1.3; 95% CI 1.1, 1.5), urban vs. rural setting (AOR 1.2; 95% CI 1.0, 1.4), and for-profit status (AOR 1.3; 95% CI 1.1, 1.5), after adjusting for resident and facility characteristics **Key implications and recommendations** • Continuity of care is negatively associated with the use of PEG tubes in hospitalized patients with advanced dementia • Post-hospital admission to a skilled nursing facility among nursing home residents with advanced dementia may interfere with the use of end-of-life care
Gustafsson et al., 2017 Sweden Randomized controlled trial Dementia identification: Medical record notes prior to index hospitalization	$n = 429$ patients admitted to two hospitals ($\geq$ 65 years of age) 212 intervention 64 (30%) AD 42 (20%) VaD 106 (50%) unspecified or other dementia mean age = 83.1 $\pm$ 6.1 female = 63% 217 control 68 (31%) AD 30 (14%) VaD 119 (55%) Unspecified or other dementia mean age = 83.1 $\pm$ 6.1	30 days, 180 days/3 years **Three transitions** • x-hospital-x-hospital	**Three transitions (30-day time frame)** • Including patients with heart failure, the rate of drug-related hospital readmission was lower among the intervention than the control group (5% vs. 11%; p =0.03) **Three transitions (180-day time frame)** • Including patients with heart failure, there was no difference in the rate of drug-related hospital readmission among the intervention and control groups (18.9% vs. 23%; p = 0.28) • Excluding patients with heart failure, the rate of drug-related hospital readmission was lower among the intervention than the control group (11% vs. 20%; p = 0.02) **Intervention** • The intervention was conducted by three clinical pharmacists on existing hospital ward teams. The pharmacists participated in rounds and conducted medication reconciliation and review, meeting throughout the study to align the advice they provided to the health care teams regarding drug selection, dosage, and monitoring during rounds.

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Table 3. *Continued*

Author, Date of Publication, Country, Study Design, Method of Identifying Individuals With Dementia	Sample, Minimum Age (Years), Mean Age (Years), Female %, Dementia %, Rural %	Trajectory Time Frame/ Study Period, Trajectory	Relevant Findings, Key Implications, and Recommendations
	female = 64% rural N/A		**Key implications and recommendations** • Among patients with dementia and heart failure, frequent readmissions may indicate need for proper follow-up for medication readjustment related to adherence issues, rather than indicating poor care quality • Medication adherence may be improved by including face-to-face meetings between the pharmacist and patient, and including relatives in drug therapy discussions
Harvey et al., 2016 Australia Retrospective cohort Dementia identification: ICD diagnosis code during index hospitalization, or in year prior to index hospitalization	n = 331,432 hospital admissions related to injury in one state (≥ 65 years of age) 58,503 admissions with dementia ≥ 80 years of age = 81.8% female = 70.9% 272,349 admissions without dementia ≥ 80 years of age = 52.5% female = 64.4% rural N/A	28 days, unspecified /10 years **Two transitions** • home-hospital-LTC **Three transitions** • x-hospital-x-hospital	**Two transitions** • Individuals with dementia were more likely to be discharged from hospital to a residential aged care facility than those without dementia (25.3% vs. 5.5%; *p* < 0.0001) (time frame unspecified) **Three transitions** • The 28-day hospital readmission rate was lower overall among individuals with dementia than among thos without (16% vs. 17.5%; *p* < 0.0001); however, there were exceptions according to injury type, specifically non-fracture arm injuries and toxic effects of non-medical substances (28-day time frame) **Key implications and recommendations** • The length of stay in hospital may be longer in individuals with dementia because they require a longer period of rehabilitation • Hospital readmission rates may be lower among individuals with dementia than among those without because the former are more likely to live with others or have better supports in place at discharge
Hsiao et al., 2015 Taiwan Retrospective matched cohort Dementia identification: ICD (*first*) diagnosis code at the start of the transition time frame	n = 51,384 individuals in the Longitudinal Health Insurance Database (> 65 years of age) 25,692 dementia ≥ 75 years of age = 68.8% female = 48.3% 25,692 matched controls without dementia ≥ 75 years of age = 67.4% female = 48.3% rural N/A	1 year/9 years **Three transitions** • x-hospital-x-hospital **Four or more transitions** • x-hospital-x-hospital-x-hospital	**Three transitions** • Individuals with dementia were more likely to be admitted to hospital two times, compared with matched controls (4.4% vs. 1.4%; *p* < 0.0001) (1-year time frame) **Four or more transitions** • Individuals with dementia were more likely to be admitted to hospital three times, compared with matched controls (2.2% vs. 0.6%; *p* < 0.0001) (1-year time frame) **Key implications and recommendations** • Dementia awareness among hospital staff must be improved and hospitalized individuals with dementia should receive long-term management after discharge
Kasteridis et al., 2016 England Retrospective longitudinal observational Dementia identification: ICD diagnosis code during hospitalization	n = 170,387 hospital admissions across England (minimum age N/A) 31,120 hospital admissions with primary diagnosis of dementia 23-25% AD 26-30% VaD mean age = 82.1-83.6 female = 61-65% rural* = 16-17% 139,267 hospital admissions with dementia admitted for treatment of an ambulatory care sensitive condition 18% AD 17-18% VaD	< 1 year/5 years **Two transitions** • x-hospital-LTC (included all types of group home care)	**Two transitions** • Individuals with dementia admitted to hospital with a primary diagnosis of dementia were more likely to be discharged to a care home than those with dementia admitted to hospital for treatment of an ambulatory care sensitive condition (19% vs. 14%, significance test not provided) (5-year time frame) **Associated factors** • Hospitalized patients with dementia had a greater risk of discharge to a care home with older age, female sex, incontinence, falls, hip fracture, cerebrovascular disease, cancer, and total number of other co-morbidities • Hospitalized patients with dementia had a lower risk of discharge to a care home if they lived in areas with a higher rate of unpaid care provision (50 or more hours/week) and a higher proportion of guaranteed pension recipients **Key implications and recommendations** • The risk of care home placement may be reduced by addressing important risk

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Table 3. *Continued*

Author, Date of Publication, Country, Study Design, Method of Identifying Individuals With Dementia	Sample, Minimum Age (Years), Mean Age (Years), Female %, Dementia %, Rural %	Trajectory Time Frame/ Study Period, Trajectory	Relevant Findings, Key Implications, and Recommendations
	mean age = 82.7-84.5 female = 64-68% rural* = 14-16% *population of less than 10,000		factors, such as referring individuals with dementia to falls or continence clinics where warranted
Kedia et al., 2017 United States Retrospective cohort Dementia identification: ICD diagnosis code during study period	n = 96,124 Medicare beneficiaries across three states (≥ 65 years of age) 1,294 co-existing dementia and cancer ≥ 85 years of age = 37.6% female = 53.4% 8,533 dementia only ≥ 85 years of age = 44.4% female = 73.1% 11,696 cancer only ≥ 85 years of age = 12.5% female = 46.6% 74,601 neither dementia nor cancer ≥ years of age = 11.9% female = 61.5% rural N/A	30 days, 1 year/1 year **Two transitions** • home-hospital-LTC • home-hospital-hospice care **Three transitions** • x-hospital-x-hospital **Four or more transitions** • x-hospital-x-hospital-x-hospital	**Two transitions** • Hospitalized individuals with co-existing dementia and cancer were more likely to be discharged to a nursing home than patients with neither dementia nor cancer (34.4% vs. 8.6%; $p < 0.05$). Discharge to LTC occurred in 35.9% of hospitalized patients with dementia alone and 7.5% of hospitalized patients with cancer only (1-year time frame) • Hospitalized individuals with co-existing dementia and cancer were more likely to be discharged from hospital to hospice care than patients with neither dementia nor cancer (5.9% vs. 1.4%; $p < 0.05$). Discharge from hospital to hospice care occurred in 4.1% of patients with dementia only and in 5.1% of patients with cancer only (1-year time frame) **Three transitions** • The 30-day hospital readmission rate was highest among individuals with co-existing dementia and cancer, dementia only, and cancer only, vs. neither dementia nor cancer (23.5%, 18.9%, 16.1% vs. 9.8%; $p < 0.05$) **Four or more transitions** • Among the whole sample, individuals with dementia and cancer were more likely to have three or more hospitalizations than those with neither dementia nor cancer (19.9% vs. 1.6%; $p < 0.05$). Among those with dementia only and those with cancer only, 11.9% and 5.2% were hospitalized three or more times, respectively (1-year time frame) **Key implications and recommendations** • A high rate of hospital readmission among individuals with co-existing dementia and cancer indicates competing care demands, possible neglect of critical medical issues, and possible low degree of coordinated care partially the result of co-morbid conditions • Specialists and family physicians should take a more active role in care coordination, and a "tailored health care protocol" should be developed for patients with co-existing dementia and cancer
Leung et al., 2013 China Retrospective cohort Dementia identification: Unspecified method, diagnosis at LTC admission	n = 169 residents admitted to 10 LTC facilities (minimum age N/A) AD = 100% mean age = 82.4 ± 8.1 female = 72.2% rural N/A	90 days, 1 year/6 years **Three transitions** • LTC-hospital-LTC-hospital	**Three transitions** • 14.3% of LTC residents with AD hospitalized at least one time between LTC admission and 1-year post admission, were readmitted to hospital within 90 days (90-day time frame) **Associated factors** • LTC residents with more severe cognitive impairment had fewer decreases in hospitalization frequency between LTC admission and 1-year post-admission, than those with less severe cognitive impairment (1-year time frame) • Increased medication use among LTC residents was associated with a greater number of hospitalizations at 1-year post-LTC admission compared with admission (1-year time frame) **Key implications and recommendations** • Cognition and polypharmacy among LTC residents with Alzheimer's disease should be monitored over time; interventions to reduce cognitive decline should be considered

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Table 3. *Continued*

Author, Date of Publication, Country, Study Design, Method of Identifying Individuals With Dementia	Sample, Minimum Age (Years), Mean Age (Years), Female %, Dementia %, Rural %	Trajectory Time Frame/ Study Period, Trajectory	Relevant Findings, Key Implications, and Recommendations
Mitchell et al., 2017 Australia Retrospective cohort Dementia identification: ICD diagnosis code during year of, or in year prior to, index hospitalization	$n = 12,111$ hospitalizations resulting from intentional self-harm in one state ($\geq$ 50 years of age) 427 hospitalizations of individuals with dementia $\geq$ 80 years of age = 33.5% female = 46.6% 11,684 hospitalizations of individuals without dementia $\geq$ 80 years of age = 7.2% female = 56.8% rural N/A	28 days/9 years **Three transitions** x-hospital-x-hospital	**Three transitions** • 28-day hospital readmission, adjusted for age, was higher among individuals with dementia compared to individuals without dementia (35.2% vs 23.3%; $p < 0.0001$) **Key implications and recommendations** • Individuals with dementia who intentionally harm themselves may experience more severe cognitive and physical harm than individuals without dementia, resulting in longer hospital stays • Prevention strategies should be developed to reduce self-harm among individuals with dementia, such as identifying those with co-morbid mental health conditions
Mitchell et al., 2016 Australia Retrospective cohort Dementia identification: ICD diagnosis code during year of, or in year prior to, index hospitalization	$n = 32,305$ patients with a hip fracture-related hospital admission in one state ($\geq$ 65 years of age) 8,785 dementia $\geq$ 80 years of age = 85.1% female = 73.7% 23,520 no dementia $\geq$ 80 years of age = 69% female = 71.5% rural N/A	28 days, 1 year/5 years **Two transitions** • home-hospital-LTC (low level care) • home-hospital-LTC (high level care) • home-hospital-other (community group home, boarding house, transitional living unit) **Three transitions** • x-hospital-x-hospital	**Two transitions** • Patients with dementia living at home before hospitalization for a hip fracture were more likely than those without dementia ($p < 0.0001$) to be discharged to residential aged care (25.2% vs. 8.6%), and group homes, boarding houses, or transitional living (19.6% vs. 12.4%) (1-year time frame) **Three transitions** • 28-day hospital readmission, adjusted for age, was lower among individuals with dementia hospitalized with a hip fracture than among individuals without dementia (17.3% vs. 24.4%; $p < 0.0001$) **Key implications and recommendations** • A longer length of stay in hospital among individuals with dementia may be caused by a greater negative effect of hip fractures on cognition and physical functioning among this group • Individuals with dementia who experience a hip fracture should receive rehabilitation to improve their physical functioning
Mitchell et al., 2015 Australia Retrospective cohort Dementia identification: ICD diagnosis code during year of, or in year prior to, index hospitalization	$n = 16,691$ patients with a poison-related hospital admission in one state ($\geq$ 50 years of age) 895 dementia $\geq$ 80 years of age = 50.8% female = 60.1% 15,796 no dementia $\geq$ 80 years of age = 12.7% female = 57.2% rural N/A	28 days/10 years **Three transitions** • x-hospital-x-hospital	**Three transitions** • 28-day readmission was lower among individuals with dementia than among those without dementia, hospitalized for unintentional poisoning (13.8% vs. 18.8%; $p < 0.001$) • 28-day readmission was not different among individuals with dementia than among those without dementia, hospitalized for intentional poisoning (21.0% vs. 23.0%; $p > 0.001$) **Key implications and recommendations** • As the majority of intentional and unintentional poisoning substances were medicinal, strategies to prevent poisoning should include usage of blister packs and caregiver involvement in medication regimes, and monitoring for self-harm behavior
Mondor et al., 2017 Canada Retrospective cohort Dementia identification: ICD diagnosis code or prescription drug claim prior to study enrollment	$n = 30,112$ long-stay home care clients in one province at initial home care assessment ($\geq$ years of age 50) dementia = 100% (causes not specified) mean age = 83.0 $\pm$ 7.7 female = 63% rural* = 12% *not defined	1 year/1.5 years **Two transitions** • home-hospital-LTC **Three transitions** • home-hospital-home-hospital	**Two transitions** • 29.9% of long-stay home care clients with dementia entered LTC after an acute hospitalization (1-year time frame) **Three transitions** • 13.5% of long-stay home care clients with dementia were admitted to hospital two or more times (1-year time frame) **Key implications and recommendations** • Further research is required to identify interventions to reduce the use of expensive health system use among long-stay home care clients with dementia

Table 3. *Continued*

Author, Date of Publication, Country, Study Design, Method of Identifying Individuals With Dementia	Sample, Minimum Age (Years), Mean Age (Years), Female %, Dementia %, Rural %	Trajectory Time Frame/ Study Period, Trajectory	Relevant Findings, Key Implications, and Recommendations
Noel et al., 2017 United States Chart audit and caregiver survey Dementia identification: Clinical diagnosis conducted at study enrollment	$n = 967$ intervention patients enrolled in a community-based dementia disease management program in one state (minimum age N/A) 37% AD 13% VaD 4% frontotemporal 3% Lewy body 43% mixed, other mean age = 80.3 ± 7.7 female = 63% rural*: State is predominantly rural *not defined	30 days/1 year **Three transitions** x-hospital-x-hospital	**Three transitions** • The 30-day re-hospitalization rate among the intervention group with dementia was 5%; a control group was not included **Intervention** • The MemoryCare program was delivered over a 1-year period by teams of physicians and care managers (nurse or social worker). Patient/caregiver dyads were referred by their primary care provider to receive education, counseling, and support. Individual care plans were shared with patients' primary care providers and other health care providers. **Key implications and recommendations** • Education, training, and direct involvement of caregivers in care management may improve health care system navigation and reduce hospitalization
Ono et al., 2011 Japan Retrospective cohort Dementia identification: Clinical diagnosis during index hospitalization	$n = 326$ patients admitted to a hospital ward for dementia patients, for psychological and behavioural symptoms (BPSD) (minimum age N/A) 215 female (66%) 69.3% AD 22.8% VaD 7.9% other dementia mean age = 81.7 ± 7.2 111 male (34%) 49.5% AD 42.3% VaD 8.1% Other dementia mean age = 80.7 ± 7.3 rural N/A	24 months/8 years **Two transitions** • home-hospital-LTC • home-hospital1-hospital2 **Three transitions** • home-hospital-home-hospital	**Two transitions** • 39.3% of individuals admitted to a hospital ward for dementia patients were subsequently admitted to an institution and 21.5% were admitted to a different hospital (hospital2) (2-year time frame) **Three transitions** • The hospital readmission rate was 23.3% among patients admitted to a hospital ward for patients with dementia (2-year time frame) **Associated factors** **Two transitions** • Females were more likely than males to be discharged from hospital to an institution (45.1% vs. 29.9%, significance test not provided) **Three transitions** • The rate of hospital readmission was similar between males and females (25.2% vs. 22.3%; $p = 0.582$) • Late readmissions within 4–24 months of discharge were more likely among females than males (11.6% vs. 5.4% of all readmissions; $p = 0.015$) • Among males, early readmission within the first 3 months after hospital discharge was associated with number of cohabitants at home (OR 0.66; 95% CI 0.46, 0.95) and discharge to another hospital (OR 19.12; 95% CI 3.46, 105.76) • Among females, early readmission within the first 3 months after hospital discharge was associated with length of stay (OR 1.003; 95% CI 1.00, 1.01) and discharge to another hospital (OR 24.9; 95% CI 5.70, 108.75) **Key implications and recommendations** • The causes of hospital readmission among patients admitted to a dementia ward differ between males and females • The rate of hospital readmission may be reduced by preventing complications during hospitalization and providing caregiving support

(Continued)

Table 3. *Continued*

Author, Date of Publication, Country, Study Design, Method of Identifying Individuals With Dementia	Sample, Minimum Age (Years), Mean Age (Years), Female %, Dementia %, Rural %	Trajectory Time Frame/ Study Period, Trajectory	Relevant Findings, Key Implications, and Recommendations
Oud, 2017 United States Retrospective cohort Dementia identification: ICD diagnosis code during hospitalization	*n* = 889,008 hospital admissions in one state (≥ 65 years of age) dementia = 100% (causes not specified) ≥ 80 years of age = 62.4% female = 64.4% rural N/A	1 year/9 years **Two transitions** • x-hospital-hospice care	**Two transitions** • 1.5% of hospital patients with dementia were discharged to hospice care in 2001 and 6.3% were discharged to hospice care in 2010 (1-yr time frame) **Associated factors** (2001 and 2010 combined) • The risk of discharge from hospital to hospice care was higher among patients 80 years of age and older (AOR 1.8; 95% CI 1.7, 1.8), lower among individuals of "non-white" ethnicity (e.g., African-American AOR 0.67; 95% CI 0.65, 0.70), lower among those with health insurance (e.g., Medicaid AOR 0.41; 95% CI 0.37, 0.46), higher among patients with certain non-dementia co-morbidities (e.g., malignancy AOR 3.72, 95% CI 3.61, 3.84), higher among those with a greater number of failing organs (e.g., 4 or more AOR 6.18, 95% CI 5.61, 6.82), and higher among those on mechanical ventilation (AOR 1.12, 95% CI 1.06, 1.18) **Key implications and recommendations** • The negative association between health insurance and discharge from hospital to hospice care was unexpected and should be examined in future research • Future intervention research should take into account the factors associated with discharge from hospital to hospice care found in the present study
Rudolph et al., 2010 United States Prospective cohort Dementia identification: Clinical diagnosis at study enrollment	*n* = 827 community-based participants assessed at a specialized research centre (≥ 65 years of age) AD = 100% mean age = 75.8 ± 6.2 female 58% rural N/A	4 years (mean)/15 years **Three transitions** • home-hospital-x-hospital	**Three transitions** • 47% of community-based individuals with AD hospitalized two or more times (mean time frame 4.0 ± 3.4 years) **Key implications and recommendations** • Future research should include studies to examine the prevalence and causes of hospitalization among individuals with AD, and intervention studies to prevent hospitalization
Seematter-Bagnoud et al., 2012 Switzerland Cross-sectional study Dementia identification: Clinical diagnosis during hospitalization	*n* = 1,764 patients admitted to one hospital (≥ 70 years of age) 1,038 cognitively intact mean age = 81.0 ± 6.6 female = 70% 301 CIND mean age = 83.7 ± 6.9 female = 73.1% 425 dementia mean age = 84.4 ± 6.3 female = 66.1% rural N/A	3 years/3 years **Two transitions** • x-hospital-LTC	**Two transitions** • Patients with dementia were more likely than CIND and cognitively intact patients to be admitted to a nursing home after discharge from post-acute rehabilitation (28.8% versus 7.6%, 4.2%; *p* < 0.001) (3-year time frame) • After adjusting for demographic and clinical characteristics (e.g., depressive symptoms, formal home care before admission), patients with dementia had higher odds of institutionalization than cognitively intact patients (AOR 6.1; 95% CI 4.0, 9.3) and CIND patients (AOR 5.6; 95% CI 3.2, 9.7) (3-year time frame) **Key implications and recommendations** • Future research should address the possibility that longer hospital stays among patients with dementia, compared with those without dementia, are attributable to slower rehabilitation progress or complications from dementia • Interventions should be developed to advance earlier dementia diagnosis, such as cognitive screening in hospital, and to improve care for patients with dementia in hospital

(Continued)

Table 3. *Continued*

Author, Date of Publication, Country, Study Design, Method of Identifying Individuals With Dementia	Sample, Minimum Age (Years), Mean Age (Years), Female %, Dementia %, Rural %	Trajectory Time Frame/ Study Period, Trajectory	Relevant Findings, Key Implications, and Recommendations
Sivananthan & McGrail, 2016 Canada Retrospective cohort Dementia identification: ICD (*first*) diagnosis code during the transition time frame	*n* = 6,876 individuals newly diagnosed with dementia in 1 year, in one Canadian province (≥ 65 years of age) 4,133 in the community (60%) 1,693 moved to LTC (25%) 1,050 already in LTC (15%) dementia = 100% (causes not specified) mean age = 82.3 ± 6.9 female = 62% rural* = 22.7% *not defined	1 year/10 years **Two transitions** • LTC-hospital-x **Three transitions** • home-hospital-home-hospital • LTC-hospital-LTC-hospital **Four or more transitions** • LTC-hospital-LTC-hospital-x	**Two transitions** • In the first year of diagnosis, 5% of individuals with dementia already in LTC were hospitalized once and subsequently moved to an unspecified location (1-year time frame) **Three transitions** • In the first year of diagnosis, 20% of individuals with dementia in the community (i.e., home) were hospitalized two or more times (1-year time frame) • In the first year of diagnosis, 9.3% of individuals with dementia already in LTC were hospitalized two or more times (1-year time frame) **Four or more transitions** • In the first year of diagnosis, 2% of individuals with dementia already in LTC were hospitalized two times and moved to an unspecified location (1-year time frame) **Key implications and recommendations** • Care that is integrated across sectors is necessary to reduce transitions among individuals with dementia. • Further research is warranted to identify interventions to reduce transitions during the year of diagnosis and end of life
Takacs et al., 2015 Hungary Retrospective survey Dementia identification: Medical record notes prior to hospitalization	*n* = 79 patients admitted to two hospitals (minimum age N/A) 11.4% AD 40.5% VaD 43% mixed (VaD and neurodegenerative) 5.1% other mean age = 77.6 female = 68.4% rural N/A	3 months/3 months **Two transitions** • x-hospital-LTC	**Two transitions** • 20.3% of patients admitted to hospital were transferred to a nursing home (3-month time frame) **Associated factors** **Two transitions** • Severe social situation, serious medical issues, and need for permanent medical care **Key implications and recommendations** • Better social care and more nursing home spaces are required to accommodate individuals with dementia who cannot be discharged home because of their social situation or need for medical care.
Teno et al., 2013 United States Retrospective cohort Dementia identification: ICD diagnosis code in last 6 months of life	*n*= 556,484 fee-for-service Medicare beneficiaries who died in 2000 and 2009 nationwide (> 65 years of age) 270,202 died in 2000 59,065 dementia mean age = 85.2 ± 7.2 female = 63.9% 49,735 cancer mean age = 77.9 ± 7.0 female = 49.6% 79,284 COPD mean age = 80.2 ± 7.5 female = 49.6% 286,282 died in 2009 67,861 dementia mean age = 86.2 ± 7.1 female = 68.8% 55,362 cancer mean age = 78.7 ± 7.6 female = 52.3% 91,517 COPD mean age = 81.4 ± 8.0 female = 56.2 rural N/A	Last 90 days of life/9 years **Four or more transitions** • x-hospital-x-hospital-x-hospital	**Four or more transitions** • In 2000 and 2009, 12% and 10.7% of individuals with dementia, respectively, were hospitalized three or more times in the last 90 days of life, compared with 13.2% and 14.4% of cancer patients and 17.1% and 19.9% of COPD patients (significance test not provided) (90-day time frame) **Key implications and recommendations** • Future research should further investigate trends in health service use in the last days of life in terms of patient preferences and quality of life

(Continued)

Table 3. *Continued*

Author, Date of Publication, Country, Study Design, Method of Identifying Individuals With Dementia	Sample, Minimum Age (Years), Mean Age (Years), Female %, Dementia %, Rural %	Trajectory Time Frame/ Study Period, Trajectory	Relevant Findings, Key Implications, and Recommendations
Voisin et al., 2009 France Prospective cohort Dementia identification: Clinical diagnosis at study enrollment	*n* = 686 community-based participants nationwide (minimum age N/A) AD = 100% mean age = 77.8 ± 6.8 female = 71.2% rural N/A	2 years/2 years **Three transitions** • home-hospital-x-hospital **Four or more transitions** • home-hospital-x-hospital-x-hospital	**Three transitions** • 19.8% of community-based individuals with AD were hospitalized two times (2-year time frame) • Average time elapsed between the first and second hospitalization was 176.4 days (SD 150.2) (2-year time frame) • The cause of readmission was the same cause as that for the initial hospitalization in 17.7% of cases (2-year time frame) **Four or more transitions** • 11.8% of individuals with AD were admitted to hospital three or more times (8.8% three times, 2% four times, and 1% five times) (2-year time frame) **Key implications and recommendations** • Early intervention and regular geriatric assessment should target individuals with AD to prevent and effectively manage the primary causes of hospitalization (e.g., fractures, cardiovascular disorders, and behavioural disorders)
Zekry et al., 2009 Switzerland Prospective cohort Dementia identification: Clinical diagnosis during hospitalization	*n* = 435 patients admitted to one hospital (> 75 years of age) 180 dementia mean age = 86.3 ± 6.3 female = 72.2% 48 MCI mean age = 85.0 ± 6.6 female = 64.6% 107 no dementia mean age = 84.5 ± 7.0 female = 73.4% rural N/A	2 years/2 years **Two transitions** • home-hospital-LTC	**Two transitions** • Individuals with dementia admitted to hospital were more likely to be discharged to a nursing home than individuals with MCI or without dementia (20.1% vs. 8.3%, 8.2%; *p* = 0.001) (2-year time frame) **Associated factors** • After adjusting for age, sex, and clinical characteristics (e.g., functional and nutritional status), discharge from hospital to nursing home was independently associated with severe dementia (AOR 4.17; 95% CI 1.07, 16.26; *p* = 0.05) and functional status (AOR 0.50; 95% CI 0.26, 0.99; *p* = 0.046) **Key implications and recommendations** • Management of behaviour-related to dementia, as well as follow-up and provision of support services after hospital discharge, should be targeted to address the risk of institutionalization associated with dementia severity

Note. index hospitalization = admission to the first hospital in the care trajectory; AD = Alzheimer's disease; AOR = adjusted odds ratio; CI, confidence interval; COPD = chronic obstructive pulmonary disease; ICD, International Classification of Diseases; LTC = long-term care; MCI = mild cognitive impairment; PRD = Parkinsonism-related dementia; SD = standard deviation; VaD = vascular dementia.

in Japan, that 23.3 per cent of patients first admitted to a ward for behavioural and psychological symptoms related to dementia, were readmitted to the same ward within 2 years. In a large retrospective cohort study of home care clients with dementia in one Canadian province, Mondor et al. (2017) reported that 13.5 per cent of all clients experienced two or more hospital admissions within 1 year. A separate retrospective cohort study in another Canadian province further demonstrated that 20 per cent of community-based individuals experienced two or more hospital admissions in 1 year; specifically, in the first year of the dementia diagnosis (Sivananthan & McGrail, 2016). Two separate intervention studies reported a reduction in hospital readmission rates among patients with dementia in an intervention group compared with a control group (Boltz et al., 2015; Cassel et al., 2016). In the first study, conducted in two United States hospitals, Boltz et al. (2015) found a lower 30-day hospital readmission rate among patients with dementia in the intervention compared with the control group (7% vs. 24%). Whereas the control group received staff education only, the intervention group was exposed to multiple elements: staff received family-centred education, ongoing training, and motivation; environmental and policy modifications were made, such as the addition of bedside white boards to increase communication between staff and patient/family; and patient/family education encouraged engagement in developing and communicating individualized goals and expectations. Similarly, the second study found that patients with dementia in a U.S. state who participated in a specialty palliative care program intervention had a lower rate of 30-day hospital readmission than non-participants (11% vs. 35%) (Cassel et al., 2016).

The third common trajectory that started from home, which was investigated in three studies, involved a first hospitalization followed by readmission from an unspecified location (*home-hospital-x-hospital*) (Fong et al., 2012; Rudolph et al., 2010; Voisin et al., 2009). Fong et al. (2012) considered participants of a specialized US research centre with Alzheimer's disease (AD) residing at home in the community and admitted to hospital, finding that 61 per cent were readmitted to hospital within 1 year. Two articles reported the number of times that community-based individuals with AD were admitted to hospital, with Rudolph et al. (2010) finding that 47 per cent of patients attending a community-based United States research centre were admitted to hospital two or more times over an average of 4 years, and Voisin et al. (2009) finding that 19.8 per cent of participants of a prospective cohort study nationwide in France were hospitalized two times over 2 years.

From LTC

As investigated in five articles, the trajectory originating from LTC that was most often studied involved transfer to hospital and back to LTC (Aaltonen et al., 2014; Bucher et al., 2016; Callahan et al., 2012, 2015; Givens et al., 2013). Regarding this *LTC-hospital-LTC* route, Bucher et al. (2016) reported that 91 per cent of people with dementia living in Swiss nursing homes before hospitalization were discharged to LTC over 3.5 years. Callahan et al. (2012) observed that 20 per cent of primary care patients with dementia in a U.S. state were admitted from LTC to hospital and later discharged back to LTC over an average 5-year time frame. In a later study using national data from the United States Health and Retirement study, Callahan et al. (2015) reported that individuals with dementia compared with those without were more likely to experience this route over a 12-month time frame, regardless of the stage of dementia.

From an unspecified location

Detailed in 11 articles, the most common trajectory beginning from an unspecified setting involved hospital admission and readmission (*x-hospital-x-hospital*) (Daiello et al., 2014; Davydow et al., 2014; Draper et al., 2011; Gustafsson et al., 2017; Harvey et al., 2016; Hsiao et al., 2015; Kedia et al., 2017; Mitchell et al., 2015, 2016, 2017; Noel et al., 2017). Two of the 11 articles did not report hospital readmission rates at the patient level (Daiello et al., 2014; Davydow et al., 2014); however, 30-day readmission was found to be associated with dementia by Daiello et al. (2014). A further two studies examined the effectiveness of separate interventions (Gustafsson et al., 2017; Noel et al., 2017). In a randomized controlled trial of patients with dementia admitted to two hospitals in Sweden, Gustafsson et al. (2017) determined that patients with dementia without heart failure receiving a medication reconciliation intervention exhibited a lower rate of drug-related readmission over a 6-month time frame than non-intervention patients (11% vs. 20%). Noel et al. (2017) found a 30-day readmission rate of 5 per cent among community-based patients with dementia and care partners receiving care management; however, a group for comparison was not included. The remaining seven studies included controls without dementia. Draper et al. (2011) reported a higher readmission rate among patients with dementia than controls in a 3-month time frame (40% vs. 32%) and Hsiao et al. (2015) found 4.4 per cent of persons with dementia compared with 1.4 per cent of controls were admitted to hospital two times within 1 year in a national study of Taiwan (Hsiao et al., 2015). Over time frames of 28 to 30 days, two studies identified higher readmission rates among patients with dementia (18.9–35.2%) than controls (9.8–23.3%) (Kedia et al., 2017; Mitchell et al., 2017) and three studies found lower or no difference in rates among patients with dementia (13.8–21%) compared with controls (17.5–24.4%) (Harvey et al., 2016; Mitchell et al., 2015, 2016).

Reported in six articles, trajectories characterized by hospital admission from an unspecified setting followed by transition to LTC (*x-hospital-LTC*) (Bucher et al., 2016; Daiello et al., 2014; Draper et al., 2011; Kasteridis et al., 2016; Seematter-Bagnoud et al., 2012; Takacs, Ungvari, & Gazdag, 2015) were also common. The proportion of individuals with dementia admitted to hospital from an unspecified location who transitioned to LTC ranged from 19 to 50 per cent within time frames of 3 months to 3.5 years (Bucher et al., 2016; Kasteridis et al., 2016; Seematter-Bagnoud et al., 2012; Takacs et al., 2015). Significant differences were found in all of the studies that included control patients (Daiello et al., 2014; Draper et al., 2011; Seematter-Bagnoud et al., 2012). Draper et al. (2011) determined that patients with dementia admitted to hospital in one Australian state were more likely to transfer to LTC than to their usual residence over a 2-year time frame, than were hospitalized patients without dementia. Hospitalized patients with dementia were more likely than those without dementia to be discharged to a nursing home from post-acute rehabilitation in a Swiss hospital over a 3-year time frame (28.8% vs. 4.2%) (Seematter-Bagnoud et al., 2012). Further, in a study of hospitalized Medicare beneficiaries in one U.S. state, Daiello et al. (2014) revealed that hospitalizations among patients with dementia compared with those among controls were more likely to result in discharge to LTC over 1 year (51.5% vs. 21.6% of hospitalizations).

Examined in three studies, the final common trajectory originated in an unspecified location and consisted of more than four transitions [*x-hospital-x-hospital-x-hospital*] (Hsiao et al., 2015; Kedia et al., 2017; Teno et al., 2013). Significant differences were

found in the studies that included control patients (Hsiao et al., 2015; Kedia et al., 2017). In two separate studies, each with a 1-year time frame, 2.2 per cent of individuals with dementia compared with 0.6 per cent of controls experienced three admissions in a national study of Taiwan (Hsiao et al., 2015), and 19.9 per cent of individuals with dementia and concurrent cancer across three U.S. states experienced three or more hospitalizations compared with 1.6 per cent with neither dementia nor cancer (Kedia et al., 2017). In a third study using United States national data, 10.7 to 12 per cent of individuals with dementia in the last 90 days of life underwent three or more hospital admissions compared with 13.2 to 19.9 per cent of those with cancer or chronic obstructive pulmonary disease (COPD): however, significance testing was not provided (Teno et al., 2013).

Factors Associated with Transitions and Trajectories

Eleven studies overall examined factors associated with transitions or care trajectories as a whole among individuals with dementia, with two of these studies examining variables related to more than one transition or trajectory (Aaltonen et al., 2014; Ono et al., 2011). Factors examined in each study are summarized in Table 3. Individual demographic and medical characteristics were the main focus in most studies, and both types of characteristics were examined in relation to re-hospitalization, repeated hospitalization, transition from hospital to hospice care, and transition from hospital to LTC. Organizational variables were examined in relation only to transition from hospital to LTC, and with respect to a trajectory that involved residence in two different LTC homes before and after hospitalization.

In terms of medical characteristics examined in eight studies, co-morbid dementia and depression were associated with greater odds of 30-day re-hospitalization from an unspecified location (Davydow et al., 2014). More severe cognitive impairment and increased medication use (Leung, Kwan, & Chi, 2013) increased the likelihood of re-hospitalization from LTC. Several medical factors were associated with hospitalization four or more times within 4 years of initial admission (repeated hospitalization), namely coronary artery disease, pneumonia, urinary tract infection, and fall-related fracture recorded at index admission (Chang et al., 2015). Medical characteristics related to transition from hospital to hospice care included chronic co-morbidity, failing organs, and mechanical ventilation (Oud, 2017). Medical factors also increased the risk of transition from hospital to LTC in four studies, and included severe medical issues (Takacs et al., 2015); poor functional status and severe dementia (Zekry et al., 2009); a higher number of co-morbidities, incontinence, falls, hip fracture, cerebrovascular disease, and cancer (Kasteridis et al., 2016); and percutaneous endoscopic gastrostomy (PEG) tube insertion in hospital, greater functional ability, and diabetes (Givens et al., 2013).

Demographic factors examined in relation to care transitions in four studies mainly centred on age and sex; however, other variables were also considered. Ono et al. (2011) found sex differences in early re-hospitalization from home within 3 months of discharge from a hospital ward for patients with dementia. Ono et al. reported that having fewer cohabitants predicted readmission among males but not females, and that a longer stay in the index hospital predicted readmission among females but not males. Another study reported that the likelihood of three or more hospitalizations (repeated hospitalization) among LTC residents increased for those who were younger and male (Aaltonen et al., 2014). Demographics related to transition from hospital to hospice care included older

age, "white" ethnicity, and lack of health insurance (Oud, 2017). Several demographic characteristics were associated with a higher risk of transition from hospital to LTC, including female sex (Kasteridis et al., 2016; Ono et al., 2011), male sex (Bucher et al., 2016), older age (Bucher et al., 2016; Kasteridis et al., 2016), and widowed marital status (Bucher et al., 2016). Patient demographics associated with a lower risk of transition from hospital to LTC included living in areas with a higher rate of unpaid care provision (50 or more hours/week) and a higher proportion of guaranteed pension recipients (Kasteridis et al., 2016). In examining the *LTC1-hospital-LTC2* trajectory, Aaltonen et al. (2014) found a relationship between younger age and residence in two different LTC homes pre-post hospitalization in the last 90 days of life.

Two studies also identified variables associated with care trajectories at the organizational level. The first study found that nursing home characteristics were associated with transition of residents from hospital to a skilled nursing facility, specifically large size (more than 100 beds), corporate chain status, for-profit structure, and urban versus rural location (Givens et al., 2013). The second study identified that living in sheltered housing or a specialized LTC versus a traditional nursing home was associated with residence in two different LTC homes pre-post hospitalization in the last 90 days of life (Aaltonen et al., 2014).

Discussion

This scoping review identified and classified care trajectories across multiple settings among people with dementia, and investigated the prevalence of multiple transitions and factors associated with transitions. We identified 26 distinct trajectories, including 7 trajectories that were each investigated in three or more studies and considered to be common pathways for the purpose of this review. Trajectories that involved either hospital readmission or discharge from hospital to LTC were most common. Dementia increased the likelihood of a single transition from hospital to LTC as well as hospital readmission. Factors associated with particular transitions were identified mainly at the individual level of medical and demographic characteristics. Complex care trajectories that involved numerous transitions over the course of several years were not typically considered in the studies, suggesting opportunities for future investigation.

Four of the most common trajectories involved three or more transitions consisting of hospital readmission with initial admission from home or an unspecified setting. In studies in which the overall trajectory was considered, prevalence ranged from 4.4 to 19.8 per cent for two admissions within 1–2 years (Hsiao et al., 2015; Voisin et al., 2009) and from 10.7 to 19.9 per cent for three or more admissions within 90 days to 1 year (Kedia et al., 2017; Teno et al., 2013). Variations across studies may be partly the result of differences in time frames and variations in health care systems across countries. Although studies with longer timeframes of 3 months to 1 year found that patients with dementia were more likely to be re-hospitalized than were controls (Draper et al., 2011; Hsiao et al., 2015; Kedia et al., 2017), studies with shorter periods of 28–30 days found mixed results (Daiello et al., 2014; Harvey et al., 2016; Kedia et al., 2017; Mitchell et al., 2015, 2016, 2017). These findings suggest a need to improve post-discharge care management for persons with dementia (Lin, Zhong, Fillit, Cohen, & Neumann, 2017) and a greater role for primary health care providers and community care providers in coordinating management (Austrom, Boustani, & LaMantia, 2018).

This review found that re-hospitalization factors were identified mainly in terms of medical and demographic characteristics. Previous research suggests that readmission risk may be reduced by effective discharge planning and provision of home health services after discharge, particularly for those who live alone (Lin et al., 2017). Specifically for persons in LTC, Leung et al. (2013) found that re-hospitalization risk increased with more severe cognitive impairment and medication use. Nearly half of all older adults living in LTC in Canada are prescribed at least 10 different drugs (Canadian Institute for Health Information, 2018b); however, awareness of the need to de-prescribe for older adults with dementia is growing among health care providers (Canadian Foundation for Healthcare Improvement, 2019).

Three other common trajectories involved two transitions consisting of discharge from hospital to LTC in the second transition. Among people with dementia living at home before hospitalization, the prevalence of a second transition to LTC ranged from 16 to 36 per cent compared with less than 9 per cent for those without dementia, over periods of 1–2 years (Fogg et al., 2017; Harvey et al., 2016; Kedia et al., 2017; Mitchell et al., 2016; Zekry et al., 2009). Included studies suggested that transition from hospital to LTC may follow from interactions among the cause of hospitalization, pre-existing conditions including cognitive and functional impairment, and the hospitalization experience itself. Cognitive impairment, physical assistance needs, and assessment for LTC admission performed in hospital are factors shown in prior research to increase the odds of admission to LTC (Canadian Institute for Health Information, 2017).

Several medical and demographic characteristics were also found to be associated with a single transition from hospital to LTC. Demographic factors included widowhood (Bucher et al., 2016), older age (Bucher et al., 2016; Kasteridis et al., 2016), and female sex (Kasteridis et al., 2016; Ono et al., 2011). Older females are more likely to live alone than older males (United Nations Department of Economic and Social Affairs, 2019), which may contribute to a greater risk of LTC admission. Several medical factors associated with LTC admission from hospital included severe dementia, severe medical issues, poor functional status, co-morbidity, falls, and hip fractures (Kasteridis et al., 2016; Takacs et al., 2015; Zekry et al., 2009). Older adults with dementia often have co-morbidities that can impair cognition and increase the challenge of management in the community (Austrom et al., 2018). Previous research shows that hospital administrators may follow policies that prioritize discharge to LTC rather than to home in the community, partly because of hospital capacity issues (Canadian Institute for Health Information, 2017). Initiatives to train and support care partners in combination with respite care may be effective in delaying LTC admission (Gresham, Heffernan, & Brodaty, 2018).

Interventions examined in included studies that were effective in reducing transitions focused exclusively on hospital readmissions, and were delivered either in-hospital or in-home (Boltz et al., 2015; Cassel et al., 2016; Gustafsson et al., 2017; Noel et al., 2017). Care partners were targeted in three of the four interventions, underscoring the importance of tailoring support and involving care partners in management. For example, reduced readmissions in patients with dementia were achieved after an in-hospital program trained care partners to take part in patient recovery in-hospital and after discharge (Boltz et al., 2015). Previous research advises health care providers to follow principles of family-centred care in ongoing management, such as involving care partners in conversations about medications, providing education about behaviors related to dementia, and soliciting care partners' reports about indications of pain (Austrom et al., 2018).

Findings point to opportunities for reducing the risks of transition to hospital and LTC by strengthening systems of community-based care for people living with dementia and care partners. The need for stronger community care systems is underscored by the significant effects of the COVID-19 pandemic on hospitals and LTC homes in Canada (Brown et al., 2020; Canadian Institute for Health Information, 2020). Further resources are necessary to train and support all segments of the community care system in dementia care, from paid care providers including personal care workers, first responders, and a wide range of health care professionals (e.g., family physicians and occupational therapists) to unpaid care partners who provide the majority of in-home care (Public Health Agency of Canada, 2019a). Optimal systems of community care also involve strategies for providing support with daily activities such as shopping, exercise, and technology; coordinating medical services and information sharing across paid providers; and making publicly funded home care and supportive housing widely available across jurisdictions (Boscart, McNeill, & Grinspun, 2019; Canadian Academy of Health Sciences, 2019; Canadian Institute for Health Information, 2018a). As the needs of people with dementia and their care partners vary and change as the condition progresses, practice guidelines and staffing to ensure early intervention and crisis prevention should also be widely available (Canadian Home Care Association, 2018; Canadian Institute for Health Information, 2018a).

Important opportunities for future research were revealed through this review. Complex care trajectories experienced by people living with dementia were not considered by studies in the review. In previous studies of older adults, researchers found between 131 and 240 unique transition patterns across several care settings with varying time frames (Abraham & Venec, 2016; Sato, Shaffer, Arbaje, & Zuckerman, 2010). Complex trajectories may signal fragmented care (Wang et al., 2017), particularly when occurring over a short time period. There is also a need for further study of care trajectories from the point of pre-diagnosis to end of life among people living with dementia (Boltz, 2016; Fortinsky & Downs, 2014). The longest transition time frame in the current review was 5 years (Callahan et al., 2012), signalling an opportunity for more longitudinal studies that may uncover patterns or group differences that point to discontinuity of care, such as a higher risk of transitions associated with demographic factors (Wang et al., 2017). Moreover, the risk of complex trajectories has been found to increase with the number of prior transitions experienced by people with dementia (Hathaway, 2019), further underscoring the importance of longitudinal research. Only one included study examined transition outcomes among female and male sub-populations separately (Ono et al., 2011). Sex and gender differences in care trajectories should be considered further, as sex and gender differences in neurodegenerative disorders have been observed across many studies (Tierney, Curtis, Chertkow, & Rylett, 2017). Moreover, no study in the review separately analysed transition patterns in rural and urban sub-populations. A larger share of older adults in Canada live in rural communities than in cities (Statistics Canada, 2017) yet face significant barriers in terms of accessing dementia-specific services (Morgan et al., 2015). Further investigation into rural and urban trajectories would make a substantial contribution to this research area. Finally, further research is needed concerning care trajectories among important sub-populations living with dementia. Traditionally under-represented in these studies are people with intellectual disability and young-onset dementia, and diverse ethnic groups (Boltz, 2016).

Limitations

The scoping review method allowed for a comprehensive search of the published literature and a subsequent classification of care trajectories experienced by people with dementia. The increase in published literature in recent years on the topic of multiple transitions among people with dementia fits well with the utility of scoping reviews for clarifying key concepts and knowledge gaps in emerging topics (Munn et al., 2018). It should be noted that this review did not include an assessment of the quality of included studies. Although quality assessment is not a common practice in scoping reviews (Peters et al., 2015), the lack of critical appraisal may nonetheless reduce uptake of findings into practice (Levac et al., 2010).

Grey literature and non-English articles were excluded, as were mixed-methods and qualitative studies, which may limit the generalizability of the findings. These studies were excluded because the purpose of this review was well suited to quantitative analysis, and less focused on evidence concerning the needs or experiences of people with dementia during the transition process. The latter is an important area that has been investigated with qualitative and mixed methods in previous reviews (Afram et al., 2015; Stockwell-Smith et al., 2018).

Studies included in the current review varied considerably, with some samples including those with Alzheimer's disease only, others including separate causes of dementia within the same study, and yet others not specifying the causes of dementia. Transition time frames varied from 28 days to 5 years, and studies from several different countries were included to cover the breadth of available evidence, consistent with scoping review methodology (Peters et al., 2015). These variations add to the challenge of drawing conclusions based on the findings.

Finally, it was not always possible to determine the location of settings from the information provided in the studies. Routes that began in hospital and involved a transition to a different care site directly afterward were considered to originate in an 'unspecified' location for the purpose of the review. We rationalized that individuals were admitted temporarily to hospital from permanent or long-stay living accommodations and that therefore this constituted the first transition. Unspecified locations may in fact be home, LTC, or even another hospital, thus potentially biasing the findings. It is also possible that individuals experienced more than one transition before the initial move to hospital. The time frames imposed on the observation of routes may reduce this possibility; nevertheless, it is a limitation of this study that the framework of multiple transition routes does not capture all possible patterns.

Conclusions

This review found that studies of care trajectories experienced by people with dementia most often involved hospital readmission and discharge from hospital to LTC. Studies reported that risk of hospital readmission and transition from hospital to LTC increased with dementia. Several variables contributing to transition risk were identified, mainly at the level of demographic and medical characteristics such as co-morbidity, as well as severity of both medical issues and dementia. Research opportunities exist to investigate more complex care trajectories, longitudinal trajectories of care, and trajectories experienced by sub-populations of people with dementia. Findings suggest that greater attention should be paid to care trajectories in this population, given the negative outcomes associated with transitions for people with dementia

and their care partners. Efforts to strengthen community-based systems of care as part of a multifaceted strategy to reduce transitions are recommended. These efforts should involve considerable investment in comprehensive dementia-specific training to care providers and care partners, widely available home care and supportive housing, and practical support for people with dementia to live independently for as long as safely possible in their communities.

Supplementary Materials. To view supplementary material for this article, please visit http://dx.doi.org/10.1017/S0714980821000167.

References

Aaltonen, M., Raitanen, J., Forma, L., Pulkki, J., Rissanen, P., & Jylha, M. (2014). Burdensome transitions at the end of life among long-term care residents with dementia. *Journal of the American Medical Directors Association*, **15**, 643–648.

Aaltonen, M., Rissanen, P., Forma, L., Raitanen, J., & Jylha, M. (2012). The impact of dementia on care transitions during the last two years of life. *Age and Ageing*, **41**, 52–57.

Abraham, S., & Venec, V. (2016). Transitions between care settings at the end of life among older homecare recipients: A population-based study. *Gerontology & Geriatric Medicine*, **2**, 1–8.

Afram, B., Verbeek, H., Bleijlevens, M., & Hamers, J. (2015). Needs of informal caregivers during transition from home towards institutional care in dementia: A systematic review of qualitative studies. *International Pyschogeriatrics*, **27**(6), 891–902.

Alberta Health, Continuing Care. (2017). *Alberta dementia strategy and action plan*. Retrieved 5 August 2020 from https://open.alberta.ca/publications/9781460136898.

Alzheimer's Disease International. (2020). *COVID-19 and dementia: Difficult decisions about hospital admission and triage.* Retrieved 5 August 2020 from https://www.alz.co.uk/content/adi-position-papers-on-dementia-and-covid-19.

Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology*, **8**(1), 19–32.

Austrom, M., Boustani, M., & LaMantia, M. (2018). Ongoing medical management to maximize health and well-being for persons living with dementia. *The Gerontologist*, **58**(1), S48–S57.

Boltz, M. (2016) Transitions in care for the person with dementia. In M. Boltz & J. Galvin (Eds.), *Dementia care: An evidence-based approach* (pp. 235–260). New York: Springer International Publishing.

Boltz, M., Chippendale, T., Resnick, B., & Galvin, J. (2015). Testing family-centered, function-focused care in hospitalized persons with dementia. *Neurodegenerative Disease Management*, **5**, 203–215.

Boscart, V., McNeill, S., & Grinspun, D. (2019). Dementia care in Canada: Nursing recommendations. *Canadian Journal on Aging*, **38**(3), 407–418.

Brown, E., Kumar, S., Rajji, R., Pollock, B., & Mulsant, B. (2020). Anticipating and mitigating the impact of the COVID-19 pandemic on Alzheimer's Disease and related dementias. *American Journal of Geriatric Psychiatry*, **28**(7), 712–721.

Bucher, C., Dubuc, N., von Gunten, A., & Morin, D. (2016). Measuring change in clinical profiles between hospital admission and discharge and predicting living arrangements at discharge for aged patients presenting behavioral and psychological symptoms of dementia. *Archives of Gerontology & Geriatrics*, **65**, 161–167.

Callahan, C., Arling, G., Wanzhu, T., Rosenman, M., Counsell, S., Stump, T., *et al.* (2012). Transitions in care for older adults with and without dementia. *Journal of the American Geriatrics Society*, **60**, 813–820.

Callahan, C., Tu, W., Unroe, K., LaMantia, M., Stump, T., & Clark, D., (2015). Transitions in care in a nationally representative sample of older Americans with dementia. *Journal of the American Geriatrics Society*, **63**, 1495–1502.

Canadian Academy of Health Sciences. (2019). *Improving the quality of life and care of persons living with dementia and their caregivers.* Retrieved 5 August 2020 from https://cahs-acss.ca/improving-the-quality-of-life-and-care-of-persons-living-with-dementia-and-their-caregivers/.

Canadian Foundation for Healthcare Improvement. (2019). *Appropriate use of antipsychotics.* Retrieved 5 August 2020 from https://www.cfhi-fcass.ca/WhatWeDo/appropriate-use-of-antipsychotics.

Canadian Home Care Association, 2018. *Informing the National Strategy for Alzheimer's Disease and other Dementias.* Retrieved 5 August 2020 from https://cdnhomecare.ca/wp-content/uploads/2020/03/CHCA-Survey-Report-Informing-the-National-Strategy-for-Alzheimer-web.pdf.

Canadian Institute for Health Information. (2017). *Seniors in transition: Exploring pathways across the care continuum.* Retrieved 5 August 2020 from https://www.cihi.ca/en/seniors-in-transition-exploring-pathways-across-the-care-continuum.

Canadian Institute for Health Information (2018a). *Dementia in Canada.* Retrieved 5 August 2020 from https://www.cihi.ca/en/dementia-in-canada.

Canadian Institute for Health Information. (2018b). *Drug use among seniors in Canada, 2016.* Retrieved 5 August 2020 from https://www.cihi.ca/en/drug-use-among-seniors-in-canada.

Canadian Institute for Health Information. (2020). *Pandemic experience in the long-term care sector: How does Canada compare with other countries?* Retrieved 5 August 2020 from https://www.cihi.ca/en/long-term-care-and-covid-19-international-comparisons.

Canadian Medical Protective Association. (2018). Navigating the complexities when treating patients with Alzheimer's disease and other dementias. *Perspective*, **10**(1), 4–6. https://www.cmpa-acpm.ca/en/advice-publications/browse-articles/2018/navigating-the-complexities-when-treating-patients-with--alzheimer-s-disease-and-other-dementias.

Cassel, B., Kerr, K., McClish, D., Skoro, N., Johnson, S., Wanke, C., *et al.* (2016). Effect of a home-based palliative care program on healthcare use and costs. *Journal of the American Geriatrics Society*, **64**, 2288–2295.

Chang, C., Lin, P., Chang, Y., Chen, N., Huang, C., Lui, C., *et al.* (2015). The impact of admission diagnosis on recurrent or frequent hospitalizations in 3 dementia subtypes: A hospital-based cohort in taiwan with 4 years longitudinal follow-ups. *Medicine*, **94**, e2091.

Daiello, L. A., Gardner, R., Epstein-Lubow, G., Butterfield, K., & Gravenstein, S. (2014). Association of dementia with early rehospitalization among Medicare beneficiaries. *Archives of Gerontology & Geriatrics*, **59**, 162–168.

Davydow, D., Zivin, K., Katon, W., Pontone, G., Chwastiak, L., Langa, K., *et al.* (2014). Neuropsychiatric disorders and potentially preventable hospitalizations in a prospective cohort study of older Americans. *Journal of General Internal Medicine*, **29**(10), 1362–1371.

Dawson, A., Bowes, A., Kelly, F., Velzke, K., & Ward (2015). Evidence of what works to support and sustain care at home for people with dementia: A literature review with a systematic approach. *BMC Geriatrics*, **15**, 59.

Deeks, L., Cooper, G., Draper, B., Kurrle, S., & Gibson, D. (2016). Dementia, medication and transitions of care. *Research in Social & Administrative Pharmacy*, **12**, 450–460.

Draper, B., Karmel, R., Gibson, D., Peut, A., & Anderson, P. (2011). The Hospital Dementia Services Project: Age differences in hospital stays for older people with and without dementia. *International Psychogeriatrics*, **23**, 1649–1658

Fogg, C., Meredith, P., Bridges, J., Gould, G., & Griffiths, P. (2017). The relationship between cognitive impairment, mortality and discharge characteristics in a large cohort of older adults with unscheduled admissions to an acute hospital: A retrospective observational study. *Age & Ageing*, **1**(46), 794–801.

Fong, T., Jones, R., Marcantonio, E., Tommet, D., Gross, A., Habtemariam, D., *et al.* (2012). Adverse outcomes after hospitalization and delirium in persons with Alzheimer Disease. *Annals of Internal Medicine*, **156**, 848–856.

Fortinsky, R., & Downs, M. (2014). Optimizing person-centered transitions in the dementia journey: A comparison of national dementia strategies. *Health Affairs*, **33**(4), 566–573.

Givens, J., Mitchell, S., Kuo, S., Gozalo, P., Mor, V., & Teno, J. (2013). Skilled nursing facility admissions of nursing home residents with advanced dementia. *Journal of the American Geriatrics Society*, **61**, 1645–1650.

Gresham, M., Heffernan, M., & Brodaty, H. (2018). The Going to Stay at Home program: Combining dementia caregiver training and residential respite care. *International Psychogeriatrics*, **30**, 1697–1706.

Gustafsson, M., Sjolander, M., Pfister, B., Jonsson, J., Schneede, J., & Lovheim, H. (2017). Pharmacist participation in hospital ward teams and hospital readmission rates among people with dementia: A randomized controlled trial. *European Journal of Clinical Pharmacology*, **73**(7), 827–835.

Harvey, L., Mitchell, R., Brodaty, H., Draper, B., & Close, J. (2016). The influence of dementia on injury-related hospitalisations and outcomes in older adults. *Injury*, **47**(1), 226–234.

Hathaway, J. (2019). *Long-term healthcare transition pathways among community dwelling adults with dementia in Alberta, Canada; A retrospective cohort analysis.* (Master's thesis). Retrieved 5 August 2020 from https://era.library.ualberta.ca/items/33d064c0-647d-4262-9876-f37ff252edfa.

Hirschman, K., & Hodgson, N. (2018). Evidence-based interventions for transitions in care for individuals living with dementia. *The Gerontologist*, **58**(S1), S129–S140.

Hsiao, F., Peng, L., Wen, Y., Liang, C., Wang, P., & Chen, L. (2015). Care needs and clinical outcomes of older people with dementia: A population-based propensity score-matched cohort study. *PLoS One*, **10**, e0124973.

Kasteridis, P., Mason, A., Goddard, M., Jacobs, R., Santos, R., Rodriguez-Sanchez, B., *et al.* (2016). Risk of care home placement following acute hospital admission: Effects of a pay-for-performance scheme for dementia. *PLoS One*, **11**, e0155850.

Kedia, S., Chavan, P., Boop, S., & Yu, X. (2017). Health care utilization among elderly medicare beneficiaries with coexisting dementia and cancer. *Gerontology and Geriatric Medicine*, **3**, 1–9.

Leung, A. Y., Kwan, C., & Chi, I. (2013). Residents with Alzheimer's disease in long-term care facilities in Hong Kong: Patterns of hospitalization and emergency room use. *Aging & Mental Health*, **17**, 959–965.

Levac, D., Colquhoun, H., & O'Brien, K. (2010). Scoping studies: Advancing the methodology. *Implementation Science*, **5**, 69.

Lin, P.-J., Zhong, Y., Fillit, H., Cohen, J., & Neumann, P. (2017). Hospitalizations for ambulatory care sensitive conditions and unplanned readmissions among Medicare beneficiaries with Alzheimer's disease. *Alzheimer's & Dementia*, **13**, 1174–1178.

Livingston, G., Sommerlad, A., Orgeta, V., Costafreda, S., Huntley, J., Ames, D., *et al.* (2017). Dementia prevention, intervention, and care. *Lancet*, **390** (10113), 2673–2734.

Ma, C., Bao, S., Dull, P., Wu, B., & Yu (2019). Hospital readmission in persons with dementia: a systematic review. *International Journal of Geriatric Psychiatry*, **34**, 1170–1184.

Mitchell, R., Draper, B., Harvey, L., Brodaty, H., & Close, J. (2017). The survival and characteristics of older people with and without dementia who are hospitalised following intentional self-harm. *International Journal of Geriatric Psychiatry*, **32**(8), 892–900.

Mitchell, R., Harvey, L., Brodaty, H., Draper, B., & Close, J. (2015). Dementia and intentional and unintentional poisoning in older people: A 10 year review of hospitalization records in New South Wales, Australia. *International Psychogeriatrics*, **27**, 1757–1768.

Mitchell, R., Harvey, L., Brodaty, H., Draper, B., & Close, J. (2016). Hip fracture and the influence of dementia on health outcomes and access to hospital-based rehabilitation for older individuals. *Disability & Rehabilitation*, **38**, 2286–2295

Moher, D., Liberati, A., Tetzlaff, J., Altman, D., & The PRISMA Group (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *PLoS Med*, **6**, e1000097.

Mondor, L., Maxwell, C., Hogan, D., Bronskill, S., Gruneir, A., Lane, N., *et al.* (2017). Multimorbidity and healthcare utilization among home care clients with dementia in Ontario, Canada: A retrospective analysis of a population-based cohort. *PLoS Medicine/Public Library of Science*, **14**, e1002249.

Morgan, D., Kosteniuk, J., Stewart, N., O'Connell, M. E., Kirk, A., Crossley, M., *et al.* (2015). Availability and primary health care orientation of dementia-related services in rural Saskatchewan, Canada. *Home Health Care Services Quarterly*, **34**(3–4), 137–158.

Muller, C., Lautenschlager, S., Meyer, G., & Stephan, A. (2017). Interventions to support people with dementia and their caregivers during the transition from

home care to nursing home care: A systematic review. *International Journal of Nursing Studies*, **71**, 139–152.

Munn, Z., Peters, M., Stern, C., Tufanaru, C., McArthur, A., & Aromataris, E. (2018). Systematic review or scoping review? Guidance for authors when choosing between systematic or scoping review approach. *BMC Medical Research Methodology*, **18**, 143.

Noel, M., Kaluzynski, T., & Templeton, V. (2017). Quality dementia care: Integrating caregivers into a chronic disease management model. *Journal of Applied Gerontology*, **36**, 195–212.

Ono, T., Tamai, A., Takeuchi, D., & Tamai, Y. (2011). Factors related to readmission to a ward for dementia patients: Sex differences. *Psychiatry and Clinical Neurosciences*, **65**, 490–498.

Oud, L. (2017) Predictors of transition to hospice care among hospitalized older adults with a diagnosis of dementia in Texas: A population-based study. *Journal of Clinical Medicine Research*, **9**(1), 23–29.

Peters, M., Godfrey, C., Khalil, H., McInerney, P., Parker, D., & Soares, C. (2015). Guidance for conducting systematic scoping reviews. *International Journal of Evidence-Based Healthcare*, **13**, 141–146.

Pickens, S., Naik, A., Catic, A., & Kunik, M. (2017). Dementia and hospital readmission rates: A systematic review. *Dementia and Geriatric Cognitive Disorders Extra*, **7**, 346–353.

Public Health Agency of Canada (2019a). *A dementia strategy for Canada*. Retrieved 5 August 2020 from https://www.canada.ca/en/public-health/services/publications/diseases-conditions/dementia-strategy-brief.html.

Public Health Agency of Canada (2019b). *Public health infobase. Dementia, including Alzheimer's disease, crude prevalence rate*. Retrieved 5 August 2020 from https://health-infobase.canada.ca/ccdss/data-tool/.

Ray, C., Ingram, V., & Cohen-Mansfield, J. (2015). Systematic review of planned care transitions for persons with dementia. *Neurodegenerative Disease Management*, **5**(4), 317–331.

Rudolph, J., Zanin, N., Jones, R., Marcantonio, E., Fong, T., Yang, F., *et al.* (2010). Hospitalization in community-dwelling persons with Alzheimer's disease: Frequency and causes. *Journal of the American Geriatrics Society*, **58**, 1542–1548.

Ryman, F., Erisman, J., Darvey, L., Osborne, J., Swartsenburg, E., & Syurina, E. (2019). Health effects of the relocation of patients with dementia: A scoping review to inform medical and policy decision-making. *The Gerontologist*, **59**(6), e674–e682.

Sadak, T., Zdon, S., Ishado, E., Zaslavsky, O., & Borson, S. (2017). Potentially preventable hospitalizations in dementia: Family caregiver experiences. *International Psychogeriatrics*, **29**(7), 1201–1211.

Sato, M., Shaffer, T., Arbaje, A., & Zuckerman, I. (2010). Residential and health care transition patterns among older medicare beneficiaries over time. *The Gerontologist*, **51**(2), 170–178.

Seematter-Bagnoud, L., Martin, E., Bula, C. (2012). Health services utilization associated with cognitive impairment and dementia in older patients undergoing post-acute rehabilitation. *Journal of the American Medical Directors Association*, **13**, 692–697.

Sivananthan, S., & McGrail, K. (2016). Diagnosis and disruption: Population-level analysis identifying points of care at which transitions are highest for people with dementia and factors that contribute to them. *Journal of the American Geriatrics Society*, **64**, 569–577.

Statistics Canada. (2017). *Age and sex highlight tables, 2016 census: Population by broad age groups and sex, for both sexes, Canada, by statistical area classification.* Retrieved 5 August 2020 from https://www12.statcan.gc.ca/census-recensement/2016/dp-pd/hlt-fst/as/Table.cfm?Lang=E&T=21

Stockwell-Smith, G., Moyle, W., Marshall, A., Argo, A., Brown, L., Howe, S., *et al.* (2018). Hospital discharge processes involving older adults living with dementia: An integrated literature review. *Journal of Clinical Nursing*, **27**, e712–e725.

Takacs, R., Ungvari, G., & Gazdag, G. (2015). Reasons for acute psychiatric admission of patients with dementia. *Neuropsychopharmacologia Hungarica*, **17**(3), 141–145.

Teno, J., Gozalo, P., Bynum, J., Leland, N., Miller, S., Morden, N., *et al.* (2013). Change in end-of-life care for Medicare beneficiaries: Site of death, place of care, and health care transitions in 2000, 2005, and 2009. *JAMA*, **309**, 470–477.

Tierney, M., Curtis, A., Chertkow, H., & Rylett, J. (2017). Integrating sex and gender into neurodegeneration research: A six-component strategy. *Alzheimer's & Dementia*, **3**(4), 660–667.

United Nations Department of Economic and Social Affairs, 2019. *Population facts: Living arrangements of older persons around the world.* Retrieved 5 August 2020 from https://www.un.org/en/development/desa/population/publications/pdf/popfacts/PopFacts_2019-2.pdf.

Voisin, T., Sourdet, S., Cantet, C., Andrieu, S., & Vellas, B. (2009). Descriptive analysis of hospitalizations of patients with Alzheimer's disease: A two-year prospective study of 686 patients from the REAL.FR study. *Journal of Nutrition, Health & Aging*, **13**, 890–892.

Wang, S. Y., Aldridge, M., Gross, C., Canavan, M., Cherlin, E., & Bradley, E. (2017). End-of-life care transition patterns of medicare beneficiaries. *Journal of the American Geriatrics Society*, **65**(7), 1406–1413.

Zekry, D., Herrmann, F., Grandjean, R., Vitale, A., De Pinho, M., Michel, J., *et al.* (2009). Does dementia predict adverse hospitalization outcomes? A prospective study in aged inpatients. *International Journal of Geriatric Psychiatry*, **24**, 283–291.