THE GERONTOLOGICAL SOCIETY OF AMERICA®

The Gerontologist
cite as: *Gerontologist*, 2018, Vol. 58, No. S1, S129–S140
doi:10.1093/geront/gnx152

OXFORD

Review Article

Evidence-Based Interventions for Transitions in Care for Individuals Living With Dementia

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Received: March 15, 2017; Editorial Decision Date: August 16, 2017

Decision Editor: Sheryl Zimmerman, PhD

Abstract

Background and Objectives: Despite numerous, often predictable, transitions in care, little is known about the core elements of successful transitions in care specifically for persons with dementia. The paper examines available evidence-based interventions to improve the care transitions for persons with dementia and their caregivers.
Research Design and Methods: A state-of-the-art review was conducted for research published on interventions targeting transitions in care for persons living with dementia and their caregivers through January 2017.
Results: Our review revealed seven evidence-based interventions to postpone/prevent or reduce care transitions specific to persons living with dementia. Effective approaches appear to be those that involve the individual and caregiver in establishing goals of care, educate the individual and caregiver about likely transitions in care; provide timely communication of information about the individual, create strong inter professional teams with competencies in dementia care, and implement evidence-based models of practice.
Discussion and Implications: Five essential features for consistent and supported care transitions for persons with dementia and their caregivers are recommended. Findings reinforce the need for additional research and adaptation of evidence-based transitions in care interventions.

Keywords: Alzheimer's disease, Care coordination, Transitional care

Background and Significance

Currently 5.5 million people are estimated to be living with Alzheimer's disease, a number expected to reach close to 14 million by 2050 (Alzheimer's Association, 2017). Among individuals living with dementia in the U.S., transitions between acute and subacute health care settings and home and community settings are common (Figure 1). In a nationally representative sample of older adults diagnosed with dementia, most (89.2%) had at least one or more hospital stays and 54.9% had at least one stay in a nursing home in the past year (Callahan et al., 2015). In a second study, researchers found that 19% of nursing home residents living with cognitive impairment experienced one or more health care transitions (e.g., transfer to a hospital or move to a different nursing home) and an average of 1.6 transitions in the last 90 days of life (Gozalo et al., 2011).

Transitions in care for persons living with dementia include movement across settings and between providers increasing the risk of receiving fragmented care and experiencing poor outcomes such as hospital-acquired complications, morbidity, mortality, and excess health care expenditures (Phelan, Borson, Grothaus, Balch, & Larson, 2012). Among Medicare beneficiaries living with a diagnosis of Alzheimer's disease, 77% have three or more additional chronic conditions and 95% have at least one additional chronic condition (Centers for Medicare & Medicaid, 2016). Persons living with dementia, in comparison to those without dementia, have greater odds of having potentially

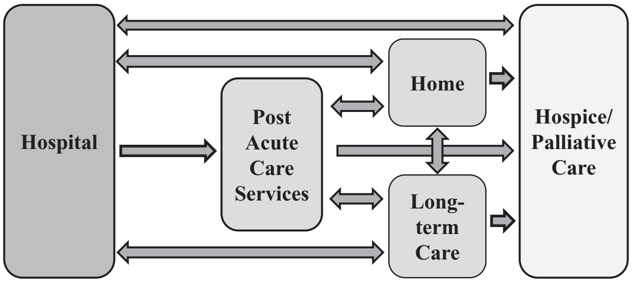

Figure 1. Common transitions in care across and between settings and providers.

avoidable hospitalizations for their chronic conditions such as diabetes and hypertension (Lin, Fillit, Cohen, & Neumann, 2013). In one recent study, experiencing new or worsening symptoms such as voice/speaking problems, urinary tract infections, blood pressure, delusions/hallucinations, falls, and “other organ specific” symptoms (e.g., diabetes, chest pain, vomiting, head injury) increased the odds of using acute care services two- to sevenfold for persons living with dementia (Sloane et al., 2017). It is estimated that 15% of hospitalizations for persons aged 65 years and older living with dementia are potentially avoidable (Lin, Rane, Fillit, Cohen, & Neumann, 2016). The resulting fragmentation in care and poor care coordination leads to many under-detected, under-evaluated, and unmet needs for persons living with dementia and their caregivers.

Transitions in care are often unnecessary, unplanned, and stressful not just for the person living with dementia but the family as well (Boltz, Chippendale, Resnick, & Galvin, 2015; Shankar, Hirschman, Hanlon, & Naylor, 2014). When an individual has to move between care settings there is a risk for a breakdown in communication, confusion about medication, lack of follow-up care, inaccuracies in information exchange, ineffective coordination of care between care providers, and inadequate patient and caregiver preparation (Gilmore-Bykovskyi, Roberts, King, Kennelty, & Kind, 2016; Kable, Chenoweth, Pond, & Hullick, 2015; Laugaland, Aase, & Barach, 2012; Shankar et al., 2014). A substantial percentage of transitions in care may be prevented by shifting care from institution to community and could result in billions of dollars in Medicare and Medicaid savings (Harrington, Ng, Laplante, & Kaye, 2012).

As the person living with dementia and their caregiver are the only common factor across levels and sites of care, a person-centered model to transitional care is viewed as a best practice to preventing adverse events and improving care quality. A “person-centered” approach considers the needs, goals, preferences, cultural traditions, family situation, and values of the person with dementia while integrating the family caregiver as an essential partner whose needs and preferences are also considered (Feinberg, 2012).

Transitional care—the planning and implementation of a move between care settings—offers an opportunity to focus on person- and family-centered care. Whereas there has been an increased emphasis in person-centered models of care transition in trials with cognitively intact older adults from hospital to home, much less attention has been paid to individuals living with dementia experiencing transitions in care between the hospital and home or residential settings and delaying moves to residential settings. Consequently, clinicians are not trained in best practices for transitional care, organizations do not have processes in place to facilitate smooth care transitions, and persons with dementia and their caregivers are not aware of the likelihood of common care transitions. The purpose of this paper is to provide an overview of available evidence-based interventions to improve transitions in care for persons living with dementia and their caregivers and provide practice recommendations for improving transitions in care going forward.

Methods

A state-of-the-art review was conducted for research published on transitions in care for persons living with dementia and their caregivers through January 2017 (Grant & Booth, 2009). A search for evidence-based intervention studies or systematic reviews was completed in several electronic databases: PubMed, CINAHL, PsycINFO, EMBASE, ProQuest, and Google Scholar. Search terms included common terms for transitions in care and dementia—(“transitional care” or “care coordination” or “transfer delay” or “placement”) and (“Lewy Body disease” or “dementia” OR “amnestic, cognitive disorders” or “frontotemporal dementia” or “Alzheimer’s disease” or “cognitive impairment”)—and articles were limited to the English language. The Cochrane Collaborative was also searched for systematic reviews of any interventions that aimed to reduce, postpone, or prevent transitions in care for persons with dementia.

Each author independently reviewed title and abstract of all identified papers, applying the following inclusion criteria: (a) testing an evidence-based intervention targeting transitions in care; (b) sample includes adults with Alzheimer’s disease or other dementias; and (c) present transitions (e.g., decrease resource use, delay placement) outcomes. The reference lists of articles were also reviewed for additional relevant intervention literature. Duplicates were removed from the lists and a total of 130 papers remained for review. Of the 130 papers, 123 were excluded for one of the following reasons: no evidence-based intervention tested (n = 14), did not report care transitions outcomes for persons living with dementia (i.e., persons with dementia excluded) (n = 109). The remaining seven papers were retained for this analysis.

Results

Table 1 offers a summary of the limited available data on evidence-based, patient-interventions targeting transitions in care for persons living with dementia and their caregivers. All seven of the interventions are multicomponent and focus on delaying or avoiding unnecessary transitions and reported evidence of support for individuals living with cognitive impairments. All but one intervention were tested in the United States. Two of the seven interventions begin during a hospitalization (Transitional Care Model, Dementia Caregiver Training Program), three interventions begin in the community at home (MIND at Home, Partners in Care, NYU Model), and two occur in the long-term care setting (Geriatric Team Intervention, Goals of Care Intervention). Below each evidence-based intervention is briefly described based on its delivery characteristics (e.g., psychosocial/educational or care coordination). Key transitional care delivery characteristics are *italicized* for emphasis.

Psychosocial/Psychoeducational Interventions Shown to Delay or Postpone Care Transitions

The New York University (NYU) Caregiver Intervention

The NYU Caregiver intervention is a comprehensive support and counseling program for caregivers designed to postpone or prevent nursing home placement of persons with Alzheimer's disease (Mittelman, Haley, Clay, & Roth, 2006). Key delivery characteristics of this intervention include an *interprofessional care team*, *prompt communication* of assessment findings, *caregiver education* and support in establishing *goals of care*. Comprehensive assessments at intake and follow-up provide information about the changing physical and emotional health and social support needs of the primary caregiver and the problems associated with dementia care. After the initial assessment two individual and four family counseling sessions are held with the primary focus being improving social support for the caregiver and helping the family understand the nature of dementia and the difficulties it presents. After the six counseling sessions, caregivers and participating family members are encouraged to telephone the counselor and to participate in the support groups whenever they need additional advice and support. Spousal caregivers in the intervention group experienced a 28.3% reduction in the rate of nursing home placement of the person living with dementia in comparison to the control group (p = .03) that received a limited intervention of project newsletters twice a year and a call from a counselor to "check in" every four months (Mittelman et al., 2006). In recent years, the model has been adapted to work with adult children (Gaugler, Reese, & Mittelman, 2013) and is in the process of being implemented on a larger scale (Mittelman & Bartels, 2014).

Prince Henry Hospital Dementia Caregiver Training Program

This 10-day program is delivered to persons with dementia during psychiatric hospitalization to delay nursing home placement. Dyads of persons living with dementia and a caregiver (most often spouses) were enrolled and both stayed in the inpatient setting to receive the 10-day intervention. Key intervention characteristics provided by an *interprofessional team* (focus of key clinician in brackets) to *educate and support caregivers* over the 10 days include: (a) a focus on reducing caregiver distress (social worker/occupational therapist); (b) combating isolation (psychiatrist); (c) decreasing guilt (psychiatrist); (d) supporting new ways of thinking (psychologist/occupational therapist); (e) coping skills (psychologist/occupational therapist); (f) fitness (physiotherapist/dietician); (g) medical assessment (psychiatrist); (h) review of community services (welfare officer); (i) planning for *goals of care* (psychiatrist); and (j) behavioral symptoms (entire team). The intervention demonstrated delays in institutionalization in participants for persons living with dementia in comparison to study participants who were randomly assigned to only receive a respite stay at the hospital (p = .04) (Brodaty, Gresham, & Luscombe, 1997).

Goals of Care Intervention

This is a two-session intervention delivered to decision makers of persons living with dementia in the nursing home setting (Hanson et al., 2016; Hanson et al., 2017). *Caregivers* for the person living with dementia first view an 18-min "*Goals of Care*" decision aid video followed by a structured discussion with the *interprofessional team* at the nursing home. The decision aid video provides a variety of information on: dementia, supporting function, improving comfort, goals of prolonging life, treatments consistent with each care goal, and how to prioritize goals. Each decision makers then received a print copy of the decision aid and guide entitled "Questions to Consider in Care Planning." The caregivers in the control group were shown a video about dementia and had a traditional care plan meeting with nursing home staff. All staff at the nursing homes were provided with training on how to have goals of care discussions. Persons living with dementia in the intervention sites had half as many hospital transfers (e.g., emergency department or hospitalization) compared to those in the control condition (p = .02) (Hanson et al., 2017). Family members in the "Goals of Care" group rated the quality of communication higher than the control group (p = .05).

Table 1. Evidence-Based Care Transitions Interventions Evaluated with Persons Living with Dementia and/or Their Caregivers

Author (year)	Setting	Intervention	Design	Description of the intervention(s)	Sample	Transition in care-specific outcomes
Psychosocial/Psychoeducational Interventions						
Mittelman et al. (2006)	Home	New York University (NYU) Model	RCT	Enhanced counseling and support intervention versus usual care	406 spousal caregivers of individuals with a diagnosis of dementia	Time to placement for the spouses of the caregivers who completed the NYU enhanced counseling and support intervention group was over 1.5 years longer than that of the usual care group (HR: 0.717; $p = .03$).
Brodaty et al. (1997)	Psychiatric Hospital	Dementia Caregiver Training (DCT) Program[a]	RCT	10 day intensive psycho-educational program for caregivers. Two-thirds of the caregivers received the DCT program either immediately after randomization or after a short waitlist versus control group (no intervention)	96 caregivers of older adults diagnosed with dementia	Time to placement was statistically significantly delayed among those persons living with dementia whose family caregivers received the DCT intervention in comparison to persons living with dementia whose family caregiver was in the control group (log rank test: 4.35, $p = .04$).
Hanson et al. (2017)	Nursing Home	Goals of Care (GOC) Intervention	Cluster RCT	GOC video with structured care planning discussion versus informational video and standard care planning	22 nursing home; 302 nursing home residents with severe to advanced dementia and their family caregiver	Nursing home residents in the GOC group had half as many hospitalizations compared to the control group (Relative risk: 0.45; $p = .02$). Family members in the GOC group rated their overall quality of communication with nursing home staff higher (score: 6.0) than the control group (score: 5.6; $p = .05$) at three months. By 9 months, family members in the GOC group rated the quality of end-of-life care communication with nursing home staff higher (score: 3.9) than the control group (score: 3.1; $p = .03$).

Table 1. *Continued*

Author (year)	Setting	Intervention	Design	Description of the intervention(s)	Sample	Transition in care-specific outcomes
Care Coordination Interventions						
Naylor et al. (2014)	Hospital to Home	Transitional Care Model (TCM)	CER	Augmented Standard Care (ASC) versus Resource Nurse Care (RNC) versus TCM	202 hospitalized older adults with a diagnosis of dementia or significant cognitive deficits in orientation, recall or executive function and 202 family caregivers	Time to first rehospitalization was longest for those in the TCM, followed by RNC and then ASC, with 25% of the TCM group rehospitalized by day 83 versus day 58 in the RNC group and day 33 in the ASC group. Rehospitalization or death was accelerated for both the ASC and RNC groups by a factor of 1.75 and 1.93, respectively, in comparison to the TCM group (p = .05 and p = .02, respectively.)
Samus et al. (2014)	Home	MIND at Home	RCT	Dementia care coordination versus usual care	303 community dwelling older adults that met criteria for dementia or cognitive disorder not otherwise specified (DSM-VI-TR) and a reliable study partner	The MIND at Home group had a significant delay in time to all-cause transition from home and the adjusted hazard of leaving the home was decreased by 37% (HR: 0.63; p = .01) and remained in their home 51 days longer (log rank test: 4.1; p = .02) compared to the control group.
Bass et al. (2014)	Home	Partners in Dementia Care (PDC)	RCT	Care coordination program versus usual care	328 veterans with a diagnosis of dementia in their medical record	The PDC group with greater cognitive impairment at 6 months postenrollment and more behavioral symptoms at baseline had fewer hospitalizations (−0.29 and −0.26, respectively; p = .01, both) and among those with behavioral symptoms at 6 months post enrollment had fewer emergency department visits (−0.27; p = .02) in comparison to the control group.

Table 1. *Continued*

Author (year)	Setting	Intervention	Design	Description of the intervention(s)	Sample	Transition in care-specific outcomes
Bellantonio et al. (2008)	Assisted Living	Geriatrics Team Intervention (GTI)	RCT	GTI consisted of four systematic inter professional geriatric team assessments during the first 9 months living in an assisted living community versus standard medical care.	100 older adults with dementia who relocated to an assisted living	Analyses of the primary outcomes revealed reductions in the risk of unanticipated transitions, including hospitalizations (45%), ED visits (12%) and nursing home placement (11%), as well as death (63%), for the GTI group versus standard care, though not statistically significant.

Note: CER = Comparative Effectiveness Research; CI = Confidence interval; HR = Hazards ratio; RCT = Randomized Control Trial.
[a]Australia.

Care Coordination Interventions Shown to Postpone Transitions in Individuals Living With Dementia

The Transitional Care Model (TCM)

The TCM is a rigorously tested comprehensive advanced practice nurse led model of care that starts in the hospital and continues through skilled nursing facilities and back to the community (Naylor et al., 1994; Naylor et al., 1999; Naylor et al., 2004). The TCM focuses on person-centered care; education and promotion of self-managed care; continuity, collaboration, and care coordination with all members of the *interprofessional team* (Hirschman, Shaid, McCauley, Pauly, & Naylor, 2015). In a recent comparative effectiveness trial, the hospital to home TCM was tested against other lower dose evidence-based hospital only interventions each designed to improve care transitions for persons living with cognitive impairment and their family caregivers. The TCM intervention consisted of visits by the advanced practice nurse in the hospital and at home to discuss *goals for care* and establish the care plan; a *collaborative visit* with the older adult, *caregiver* and at least one of their physicians; telephone calls and advanced practice nurse *availability 7 days a week for education and support* (Hirschman et al., 2015). The TCM supplemented care during the hospitalization, supported the discharge planning process and substituted for skilled home care nurses, when appropriate. The advanced practice nurses completed additional training on managing dementia and delirium in addition to the TCM educational training. Older adults who received the TCM had a longer time to first rehospitalization or death compared to the lower-dose hospital only interventions (TCM: 83 days; RNC: 58 days; ASC: 33 days) (McCauley, Bradway, Hirschman, & Naylor, 2014). The 30-day rehospitalization rates in this trial for the TCM group (9%) were half as much as those in the lower dose hospital only intervention groups (19% and 22%) (Naylor et al., 2014). Rehospitalization or death was accelerated for both the ASC and RNC groups by a factor of 1.75 and 1.93, respectively, in comparison to the TCM group (p = .05, p = .02, respectively) (Naylor et al., 2014). Findings from this trial were similar to prior randomized trials and comparative effectiveness research TCM studies with cognitively intact older adults (Naylor et al., 1999; Naylor et al., 2004; Naylor et al., 2013).

MIND at Home

The MIND at Home intervention is 18 months of care coordination designed to link persons living with dementia and their caregivers to community-based agencies, medical and mental health care providers, and community resources (Samus et al., 2014). MIND at Home is delivered by an *interprofessional team* who conduct comprehensive in-home dementia-related needs assessments and provide individualized plans to establish *goals of care* and implementation. The team uses six basic care strategies: resource referrals, attention to environmental safety, *dementia care education*, behavior management skills training, informal counseling, problem-solving, as well as on-going monitoring, assessment and *planning for emergent needs*. Each component of the intervention is based on best practice recommendations and evidence from prior research, and is combined for maximum impact. Results from the MIND at Home trial support that a home-based dementia care coordination included longer time to transition from home or death (remained in their home 51 days longer, p = .02) and reduced risk of leaving the home by 37% in comparison to the control group (Samus et al., 2014). More recent results demonstrated that MIND at Home participants had increased use of dementia-related outpatient medical care and nonmedical supportive community services, a combination that may have helped participants remain at home longer (Amjad et al., 2017).

Partners in Dementia Care (PDC)

The PDC model is a coaching model designed to support people living with dementia and their *caregivers* to generate an action plan that is in line with their preferences and *goals for care* (Bass et al., 2014; Judge et al., 2011). This model has been tested in the Veterans Administration (VA) health system. In a recent trial, each veteran in the PDC group worked with a care coordinator (a social worker, nurse, or other helping profession degreed individual) to develop the content and steps to be addressed in the *goals of care* (Bass et al., 2015). Copies of action plans were provided in writing by mail to the veteran and their family member and the detailed plan was kept in the VA medical record. The assessment and care plan were *revisited on an ongoing basis*. In comparison to the usual care group, the veterans in the PDC group with high baseline behavioral symptoms had 32.0% fewer hospitalizations and veterans in the PDC group with greater cognitive impairment at 6 months after the start of the intervention had 26.9% fewer hospitalizations (p = .01, both) (Bass et al., 2015). There were 28.6% fewer emergency department visits among veterans with more behavioral symptoms at 6 months in the intervention group in comparison to the unusual care group (p = .02) (Bass et al., 2015).

Geriatrics Team Intervention

This intervention consists of four systematic, *interprofessional assessments* conducted by a team of clinicians including a geriatrician or geriatrics advanced practice nurse, a physical therapist, a dietitian, and a medical social worker. The assessment was completed during the first 9 months of the person living with dementia moving to the assisted living. The geriatrician and geriatrics advanced practice nurse conducted medical and cognitive evaluations. The physical therapist evaluated physical function, gait, and balance and assessed the need for ongoing physical therapy and assistive devices. The dietitian evaluated nutritional status and provided dietary recommendations. The medical social worker assessed guardianship issues, long-term planning, and the psychosocial adjustment of the residents and families. Following assessments, the team, together with staff nurses, meet bimonthly to discuss the most recent assessments and establish *goals of care* with the primary care physician, the Assisted Living director, and *families*. Members of the team were available for *in-person or telephone consultation* with Assisted Living staff members throughout the study. While not statistically significant, individuals who received the intervention had a reduced risk of any unanticipated transition (13%), permanent relocation to a nursing facility (11%), emergency department visits (12%), hospitalization (45%) in comparison to persons living with dementia in the assisted living setting who received usual care (Bellantonio et al., 2008).

Discussion

With this review, we sought to summarize current evidence about interventions that improve transitions in care for persons living with dementia and their caregivers. In our review of the seven evidence-based interventions (see Table 1) that included transitions in persons living with dementia, successful interventions were those that included five key elements: (a) educating the individual and caregiver about likely transitions in care and ways to delay or avoid the transition; (b) providing timely communication of information among everyone involved, including the individual, caregiver and care team; (c) involving the individual and caregiver in establishing goals of care (person-centered); (d) comprising a strong collaborative interprofessional team; and (e) implementing evidence-based models of practice. Each evidence-based intervention targeted the individual living with dementia and a family caregiver and required the person or persons delivering the intervention to have a specific skill set (e.g., counselor, nurse, physician) or complete educational trainings to develop a set of competencies to work with the population, which sets these interventions apart from other transitional care interventions with cognitively intact older adults.

These key elements are in line with recent systematic reviews of best practices for care transitions for frail older adults without dementia (Allen, Ottmann, & Roberts, 2013; Chenoweth, Kable, & Pond, 2015; LaMantia, Scheunemann, Viera, Busby-Whitehead, & Hanson, 2010; Pimouguet, Lavaud, Dartigues, & Helmer, 2010; Ray, Ingram, & Cohen-Mansfield, 2015; Somme et al., 2012; Tam-Tham, Cepoiu-Martin, Ronksley, Maxwell, & Hemmelgarn, 2013). These reviews highlight the missing of persons living with dementia and their caregivers. Challenges that are unique to transitions among persons living with dementia include the need for dementia care expertise among the team, the reliance on the caregiver as an essential member of the team, the need for caregiver education and preparation, and the challenges of behavioral symptom management as part of the goals of care conversation. Nonetheless, these reviews suggest that the best outcomes for persons at high risk for care transitions, such as individuals living with dementia, are associated with care that is person-centered in that is coordinated, responsive, and tailored to individual needs and preferences. Thus, best practice recommendations involve successfully connecting medical, social and supportive care professional and caregivers over the course of dementia to achieve person-centered outcomes in transitions between care settings.

Moreover, while evidence-based transitional care intervention studies aimed at preventing transitions such as hospitalizations or rehospitalizations are numerous, our findings suggest that for most of these studies persons living with dementia were included in only a limited way or no detailed evidence of the impact of these interventions on transitions in care for persons living with dementia was published at the time of this search (through January 2017). It is likely that interventions such as Care Transition Intervention (Coleman, Parry, Chalmers, & Min, 2006); INTERACT II, (Ouslander, Bonner, Herndon, & Shutes, 2014); BOOST (Williams et al., 2014); and Project RED (Jack et al., 2009; Mitchell et al., 2014) are being used and adapted or modified for persons living with dementia in real world settings. Going forward, rigorous assessment and sharing of transitions outcomes from these efforts for persons living with dementia is needed. More attention needs to be put into well-conducted studies to understand the barriers and facilitators of adapting these interventions in dementia care practice.

Finally, most persons living with advanced dementia eventually move to long-term care settings, and for many this is the setting of death. However, there was a notable gap in the reviewed literature in terms of studies that examined transitions to palliative or end-of-life care. One Cochrane review on respite care found no evidence supporting the role of respite in delaying time to institutionalization (Lee & Cameron, 2004). Nonetheless, decisions about transitions should also be guided by the advance directives of the person living with dementia; if the individual or their surrogate decision maker so wishes, no transition may be the best decision. Any transition in care as life draws to a close is intrusive, stressful, and can negatively affect quality of life.

Limitations

While we aimed for a transparent, systematic, and pragmatic approach in this review, our conclusions are limited by factors common to literature reviews including the selection of search terms, the sources searched, and the inclusion criteria. The interventions included in this review represent the breath of approached, but may not represent the depth of evidence in transitional care interventions for persons living with dementia. For example, we did not assess each individual intervention for risk of bias or effect estimates. In addition, several strategies that have been suggested for preventing unnecessary hospitalizations were not found in our review. These include adaptations to the living environment and increasing participation in activities (Spijker et al., 2008). Our recommendations to follow are therefore grounded on the existing, albeit limited, evidence base.

Recommendations

In the course of the review, five themes emerged and were used to develop the following recommendations to guide transitional care interventions for persons living with dementia:

1. Prepare and educate persons living with dementia and their family caregivers about common transitions in care.

   Preparing and educating persons living with dementia and their caregivers about transitions in care should occur before, during and after transitions. Because family caregivers are integral to the care of individuals living with dementia, it is important to understand their need for information about common transitions, including across care settings, such as home to hospital or skilled nursing facility, nursing home to emergency department; within care settings, such as from an emergency department to an intensive care unit; or from one team of clinicians or care providers to another. For example tools are publically available from the Alzheimer's Disease Education and Referral Center (ADEAR) NICHE - Nurses Improving Care for Health System Elders and the Alzheimer's Association that can be provided to persons living with dementia and their caregivers to help them prepare for the possibilities of hospitalization (Alzheimer's Disease Education and Referral Center, 2017, NICHE, 2017b; NICHE, 2017c) and transition to rehabilitation or long-term care settings such as nursing homes or assisted living (NICHE, 2017a).
2. Ensure complete and timely communication of information between, across and within settings.

   Individuals living with dementia are frequently transferred across facilities without essential clinical information. Careful attention is essential to ensure a safe "handoff." Finding timely and standardized ways to share medical records and advance care planning forms between patients, caregivers, and providers throughout transitions is needed (Borson et al., 2016). Linking electronic health records across care settings also offers this potential. Open communication between providers, across settings, and within organizations or clinical practices is essential (both written and verbal). Assisting persons living with dementia and their caregivers in accessing and sharing information in a person- and family-centered way can help to avoid poor outcomes often associated with transitions in care (e.g., rehospitalizations, emergency department visits, medication errors, and caregiver stress). Information must be clinically meaningful, appropriate in amount; it should be communicated by a method useful to the receiving site of care. Achieving these objectives by using standardized forms or standardized approaches to communicate hand-offs can increase the accuracy of information and minimizes risk of error.
3. Evaluate the preferences and goals of the person living with dementia along the continuum of transitions in care.

   Revisiting preferences and goals for care, including treatment preferences, advance directives, and social and living situation, while the person living with dementia can participate is essential during transitions in care. If a person living with dementia is unable to participate, including caregivers or others who know the person well is vital. After any hospitalization or other significant change requiring a transition in care or level of care, a review and reassessment of the preferences and goals of the person living with dementia should include an assessment of safety, health needs, and caregiver's ability to manage the needs of the person living with dementia. This requires improved competencies of the entire interprofessional team in conducting goals of care conversation, and more effective processes to ensure appropriate assessments are performed before the decision to move a person with dementia to another setting of care is made.

4. Create strong interprofessional collaborative team environments to assist persons living with dementia and their caregivers as they make transitions.

   Creation of a strong interprofessional collaborative team environment to support the person living with dementia throughout transitions in care is crucial. Each member of the team needs to have a basic set of competencies in the fundamentals of caring for individuals living with dementia at all stages and the needs of family caregivers (Burke & Orlowski, 2015). All of the evidence-based interventions described here were specifically designed to address the challenges for individuals living with dementia and other complex chronic conditions as well as the needs of their family caregivers. For example, in the MIND study case managers were trained in dementia care management over a 4-week period of time (Amjad et al., 2017; Samus et al., 2014), in another study, Naylor and colleagues (2014) developed a set of web-based education modules focused on how to manage the care needs of older adults living with dementia and their family caregiver as they transition from the hospital to home (McCauley et al., 2014). Furthermore, this type of work requires continuity of the same clinicians (whenever possible) to support the person living with dementia and their family as they move between providers and across setting. Every member of the health care team must be accountable and responsive to ensure the timely and appropriate transfer of responsibility to the next level or setting of care. Optimally clinicians from the sending site of care should maintain responsibility for individuals with dementia until the caregivers at the receiving site assume clinical responsibility.

5. Initiate/Use evidence-based models to avoid, delay, or plan transitions in care.

   The seven evidence-based models of care in this review focused on avoiding unnecessary transitions (such as hospitalization, or emergency department visits), delaying or supporting placement in residential care settings (such as nursing homes or assisted living communities). Although many evidence-based models have excluded or limited the inclusion of persons living with dementia, adaptations of these models should be considered whenever possible to improve transitions. Among the interventions that targeted hospitalizations and emergency department visits, it is important to note that these events are often tied to nondementia-related conditions. Furthermore, targeting avoidable hospitalizations or rehospitalization for persons living with dementia has the potential to interrupt poor outcomes more common with this population such as risk of delirium (Fick, Steis, Waller, & Inouye, 2013; Watkin, Blanchard, Tookman, & Sampson, 2012) and falls (Meuleners, Fraser, Bulsara, Chow, & Ng, 2016). As evidence-based models of care are adapted and modified to meet the needs of persons living with dementia transitioning between, across and within settings of care it is critical to share the findings from these adapted transitions in care models.

Conclusion

Taken as a whole, research on transitional care interventions for persons with dementia is in an early development stage. Most research on transitions in care has not focused on older adults with dementia, and our review revealed few trials testing interventions to postpone/prevent or reduce negative outcomes associated with care transitions specific to persons living with dementia. Nonetheless, the shift in dementia care from institution to community means that interventions to support or prevent/postpone transitions in care will continue to be common for persons living with dementia. At the same time, evidence is mounting that efforts to ensure continuity of care for individuals with dementia during care transitions results in improved outcomes for the individual and their caregivers.

As the population of individuals living with dementia continues to grow for the near future finding ways to best meet their needs and more fully understand care transitions from diagnosis to death are needed. Recommendations for best practices for transitions of care for high risk older adults currently exist in Clinical Practice Guidelines such as Transitions of Care in the Long-Term Care Continuum and Acute Change of Condition in the Long-Term Care Setting (e.g., INTERACT) (American Medical Directors Association (AMDA), 2010; Ouslander et al., 2014), and documents available through the National Transitions of Care Coalition (NTOCC). While these recommendations offer promising approaches for reducing unnecessary transitions (Ingber et al., 2017), this evidence needs to be expanded to consider if it meets the unique needs of persons living with varying stages of dementia and their caregivers.

It takes a team to prevent avoidable transitions and to safely manage necessary transitions in care for persons living with dementia. The evidence supports that when health care team members effectively communicate with each other across care settings and with caregivers, persons with dementia can be safely transitioned with minimal complications. When caregivers are educated about, and involved in, care transition decisions rehospitalizations rates and lengths of stay decline and nursing home admissions can be delayed (Gitlin & Wolff, 2011).

Putting these five recommendations into practice will require a shift in current health care policies and practices.

The growing need for services that reduce unnecessary transitions or support necessary transitions can act as drivers for program innovation. For example, most health care settings require infrastructure support to involve caregivers in care transitions, and is at the heart of new initiatives such as the AARP initiated "Caregiver Advise, Record, Enable (CARE) Act" (AARP, 2014). In addition, there is a need to compensate the health care team for the required time to adequately assess the needs of both persons living with dementia and caregivers or provide the necessary education to caregivers (Alzheimer's Association, January 2017). While implementing evidence-based transitional care interventions offers the potential for cost savings by avoiding care complications, this has yet to be realized or captured. As a result, changing reimbursement structures to support evidence-based transitional care will require policies (such as the "Health Outcomes, Planning, and Education [HOPE] for Alzheimer's Act" S. 857/H.R. 1559) that recognize the essential role of caregivers and the potential benefits for persons with dementia, their caregivers and society.

Funding

This paper was published as part of a supplement sponsored and funded by the Alzheimer's Association.

Conflict of Interest

None reported.

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