

REVIEW ARTICLE

An integrative review of measures of transitions and care coordination for persons living with dementia and their caregivers

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Abstract

Introduction: High rates of hospital visits and readmissions are common among persons living with dementia, resulting in frequent transitions in care and care coordination. This paper identifies and evaluates existing measures of transitions and care coordination for persons living with dementia and their caregivers.

Methods: This integrative review builds off a prior review using a systematic search of online databases (PubMed, EBSCO, CINAHL, PsycInfo, and Scopus) to identify records and locate reports (or articles) that use measures of care transitions and care coordination. Identified measures were compared to the Alzheimer's Association's Dementia Care Practice Recommendations to evaluate strengths and weaknesses of the measure in this population, such as if measures were person- and family-centered.

Results: Seventy-one reports using measures of transitions in care and care coordination for persons living with dementia and their caregivers were identified. There were multiple measures identified in some reports. Three main areas of measures were classified into: identification of the population (3 measures, 8 reports), transitional care and care coordination delivery (14 measures, 17 reports), and transitional care and care coordination outcomes (e.g., health-care use, cost, and mortality; 17 measures, 60 reports). A strength of the three main areas of measures was that a portion of the measures were person- and family-centered. Variability in the operational definitions of some measures and time intensiveness of collecting the measure (e.g., number of items, the time it takes to complete the items) were common weaknesses.

Discussion: Transitions and care coordination measures are varied across studies targeted at persons living with dementia and their caregivers. Existing measures focus heavily on outcomes, specifically health-care resource use, and cost, rather than the elements of transitional care or care coordination. Future measure development focused on care transitions and service coordination is needed.

KEYWORDS

care coordination, care management, measurement, planning, transitional care

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1 | INTRODUCTION

More than 6 million people are currently estimated to be living with Alzheimer's disease and other dementias (hereafter dementia) in the United States, a number expected to increase to \approx 13 million by 2050.¹ Dementia is the fifth leading cause of death and the only leading cause of death without effective disease-modifying treatments.¹ People with dementia typically have at least \geq 3 other conditions (79%), and nearly all people living with dementia (96%) have at least one or more additional chronic conditions.² Individuals living with dementia in the United States have more hospital stays and emergency department visits than individuals without dementia.^{1,3}

In 2018, the Alzheimer's Association released the Dementia Care Practice Recommendations (DCPR) to provide a framework that shifts the characterization of persons living with dementia and their caregivers from inevitable functional decline to one that characterizes the full spectrum of experiences, including emphasizing well-being and personhood.⁴ The DCPR represents a new practice framework for health-care providers to assess and intervene in psychosocial aspects of person- and family-centered care across the dementia trajectory. The DCPR includes nine domains of quality dementia care, including person- and family-centered care; detection and diagnosis; assessment and care planning; medical management; information, education, and support; ongoing care for behavioral, psychological, and functional symptoms; staffing; supportive and therapeutic environments; and transitions and coordination of services. To characterize and improve these domains in clinical practice, there is a critical need to identify measures that effectively capture the full range of the dementia experience within this new framework of care. This paper focuses on measures related to care transitions and the coordination of services.

2 | BACKGROUND

Care transitions are movements between locations of care (e.g., hospital to home, home to long-term care settings, etc.), and care coordination is defined as purposefully organizing the care for a patient and communicating that information to all parties involved in the patient's care to assist in the delivery of health-care services and including transitional care (i.e., the planning and implementation of a move between care settings).^{5,6} Persons living with dementia often experience more care transitions over a shorter time than those without dementia, with the highest frequency among those in the moderate to severe stage.^{7,8} While there is a high risk for poor outcomes for all older adults during care transitions (e.g., medical errors, unnecessary treatments, rehospitalizations), persons living with dementia and caregivers have the added risk of cognitive impairment impacting their ability to independently navigate the health-care system.⁹ Of greatest concern to patients and caregivers is managing and negotiating care with multiple providers, managing illness, and psychosocial support and coping.¹⁰ Additionally, a recent review of $>$ 1.8 million hospital discharges of older adults with a dementia diagnosis highlighted that

RESEARCH IN CONTEXT

- 1. Integrative review:** The authors reviewed the literature using standard literature databases (e.g., PubMed, Scopus, EMBASE, CINAHL, and PsycInfo). Using the Dementia Care Practice Recommendations (DCPR) for Transitional Care and Care Coordination as a framework, publications that used measures and outcomes related to care transitions and care coordination were reviewed and cited.
- 2. Interpretation:** Our findings highlight the variety of measures used to identify the population in need of or who would benefit from transitional care or care coordination services, evaluation of the transitional or care coordination services delivered, and outcomes (e.g., health-care resource use, patient mortality, etc.).
- 3. Future directions:** While a variety of measures are available to capture aspects of transitional care and care coordination, measures focused on person- or family-centered transitions and care coordination, and implementation processes are needed.

40% of all-cause hospitalizations were potentially avoidable, leaving an opportunity for intervention.¹¹

Effective transitional care and care coordination interventions can reduce or postpone care transitions for persons living with dementia.⁹ The Transitional Care and Care Coordination DCPR highlights five essential features of consistent and supportive care transitions for persons living with dementia and their caregivers.^{4,9} Recommendations include preparation and education about common transitions; complete and timely communication between, across, and within settings; evaluation of preferences and goals; interprofessional team collaboration; and initiating the use of evidence-based care models.^{4,9}

However, a gap remains in our knowledge of the measures that are available to evaluate care transitions and care coordination for persons living with dementia and their caregivers. In their review of evidence-based care transition interventions, Hirschman and Hodgson⁹ found only seven articles testing evidence-based interventions for persons living with dementia that targeted transitions in care. To translate the DCPR into practice and provide effective transitional care and care coordination, researchers and clinicians need to understand the measures that are available to assess transitional care and care coordination and evaluate the quality of those measures according to the principles of the DCPR (e.g., person- and family-centeredness, accessibility, and consistency). The objective of this integrative review is to: (1) describe existing measures and measurement strategies of transitions in care and care coordination for persons living with dementia; (2) evaluate the quality of the existing measures according to the DCPR; and (3) make recommendations regarding future directions, including identifying gaps in measurement.

3 | METHODS

3.1 | Study design

To meet the objectives of this review, we completed a comprehensive search of peer-reviewed literature using integrative review methods of knowledge synthesis.¹² Integrative literature review methods are best suited to the aims of the study because they allow the reviewer to evaluate the strength of scientific evidence, identify gaps, and generate opportunities for future research.¹²

3.2 | Rationale for search strategy

In characterizing transitional care and care coordination interventions for the DCPR, Hirschman and Hodgson⁹ reviewed the literature using the search terms described in section 3.3, but applied more restrictive inclusion criteria, as their focus was specifically on intervention studies. Therefore, the inclusion criteria and focus of this integrative review were expanded to include non-intervention studies. This expansion was to ensure a more comprehensive search of measures to identify those that are most likely to meet the call of the DCPR.

3.3 | Search strategy

A rigorous and systematic search strategy was used. To represent the full spectrum of health services involved in transitional care and care coordination delivery and research, the following databases were searched: PubMed, Scopus, EMBASE, CINAHL, and PsycInfo. Consistent with those used in Hirschman and Hodgson,⁹ search terms included: ("transitional care" or "care coordination" or "transfer delay" or "placement") and ("Lewy body disease" or "dementia" OR "amnesic, cognitive disorders" or "frontotemporal dementia" or "Alzheimer's disease" or "cognitive impairment"). This literature search was completed in consultation with a library scientist and was an open date search through March 2023.

3.4 | Inclusion criteria

Literature (or records) was included if it: (1) had an element of transitional care or care coordination service (using definitions stated in the Introduction), (2) described measures relevant to transitions in care or care coordination, (3) exclusively included persons living with dementia and/or caregivers of persons living with dementia in the study sample, (4) was a peer-reviewed research study (excluded letters to the editor, case reports, protocols, and conference abstracts), and (5) was available in English. Reference lists from relevant systematic review articles were combed for additional records that met inclusion criteria, but the reviews themselves were not included. Records that did not meet the inclusion criteria were excluded from this integrative review.

After duplicate records from the search results were removed, a total of 2502 records remained for review (see Preferred Reporting Items for Systematic Reviews and Meta-Analyses diagram¹³ in Figure 1). All authors reviewed record titles and abstracts according to inclusion and exclusion criteria. Using the title and abstract 2227 records were excluded for not meeting basic eligibility criteria. A total of 275 reports (or articles) were retained and full text reviewed. Of these 275 reports, 108 did not have an element of transitional care or care coordination service, 45 did not include transitional care or care coordination measures, 41 did not exclusively include persons living with dementia or caregivers of persons living with dementia, 25 did not fit report type, and 14 were relevant systematic review articles. Of the 275 reports reviewed, 42 reports were included. A review of references from the 42 reports identified from database searches and the 14 systematic reviews revealed 30 new records that did not come up in the database search. The title and abstract of each of the 30 records was reviewed by all authors. Of these 30 records an additional 22 reports were included. Eight reports were excluded for the following reasons: one did not have an element of transitional care or care coordination, five did not include transitional care or care coordination measures, and two did not exclusively include persons living with dementia or their caregivers). Finally, the seven reports reviewed in the Hirschman and Hodgson DCPR for care transitions and care coordination evidence-based interventions were also included.⁹ This resulted in a final set of 71 reports as presented in Figure 1.

3.5 | Measure quality review process

For the included reports, we used a structured process to assess the quality of each measure. We used the DCPR as a framework to assess strengths and weaknesses. We evaluated if measures were actionable; person- and family-centered; included strengths-based perspectives; represented across studies; and if there was a high or low burden of completion, including accessibility, number of items, and time to complete as applicable.

4 | RESULTS

Seventy-one published reports were identified with measures of transitional care and care coordination for persons living with dementia and their caregivers. Reports were published between March 1987 and March 2023, and included community, post-acute, long-term care, and hospital settings in the United States, Canada, United Kingdom, Finland, France, Sweden, Denmark, Netherlands, Italy, Hong Kong, and Australia. Using an inductive approach that examined the characteristics of the measures related to transitional care and care coordination three categories emerged: (1) identification of population in need of or would benefit from transitional or care coordination services, (2) measures that capture transitional care and care coordination delivery (e.g., quality of care, care engagement, and satisfaction with care),

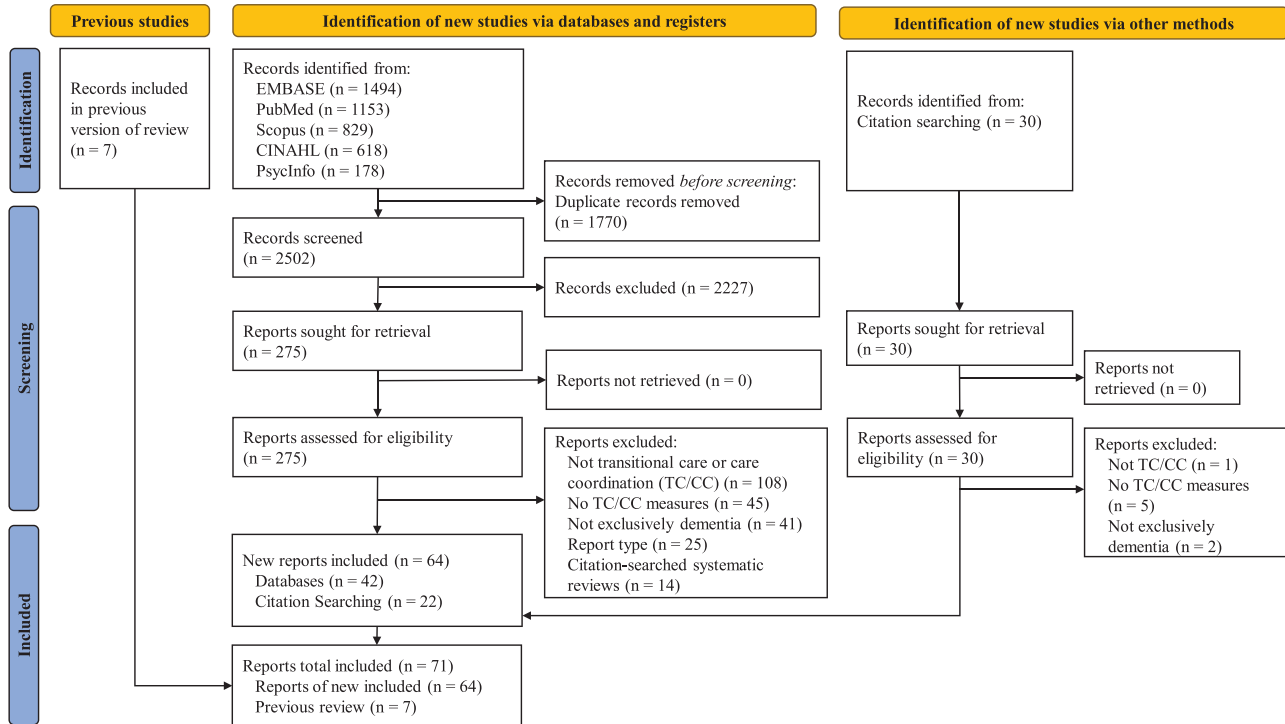


FIGURE 1 Evaluating measures of transitions and care coordination for persons living with dementia; Preferred Reporting Items for Systematic Reviews and Meta-Analyses diagram.

and (3) outcomes related to transitional and care coordination (e.g., health-care use, cost, and mortality; Table 1).

4.1 | Identification of the population

Among the 71 reports, 8 described three different measures that focused on identifying the population of persons living with dementia in need of and most likely to benefit from transitional care or care coordination.^{14–21} These measurement tools focused on assessing transitional care needs, existing care coordination, and the potential for engagement in a transitional care intervention or care coordination.

Two instruments were used to assess transitional care or care coordination needs: the Johns Hopkins Dementia Care Needs Assessment (JHDCNA) from the Maximizing Independence at Home trials,^{14,15} and unmet care needs assessment from the Partners in Dementia Care trials.^{16–19,21} Both tools assessed the needs of persons living with dementia and their caregivers and can be incorporated into the care coordination plan. The JHDCNA has been used with persons along the spectrum of cognitive impairment, from mild cognitive impairment to severe dementia. This tool includes 86 items that cover 19 domains of care and is based on best practices in dementia care.²² There are no formal psychometrics available, but concurrent validity with quality-of-life measures has been demonstrated.²² The unmet care needs assessment is based on the Chronic Care Model and includes 69 items that cover 8 domains of care and has good structural validity, with factor loadings on a single factor ranging from 0.63 to 0.84 and excellent internal consistency (Cronbach's alpha = 0.87–0.93).^{16–19,21} Care

coordination needs are actionable, and both instruments consider the person and family perspective; however, neither explicitly incorporates strengths and both are very time and resource intensive to complete, as they require the person living with dementia and/or caregiver to report on 69 to 86 items.

Engagement potential is intended to identify individuals living with dementia who are able to engage with care coordination interventions. Darlak et al. used a modified version of the Short Blessed Orientation-Memory-Concentration Test to identify individuals who are likely to be able to engage with care coordinators over the telephone.²⁰ This is an actionable measure that is person- and family-centered and includes modification that theoretically considers the strengths of persons living with dementia and their abilities to engage. However, there is also the possibility that this measure would exclude individuals who need intervention but may need to engage using alternative methods that fully consider their abilities reducing the transferability across diverse populations. Psychometric data are not available.

4.2 | Transitional care and care coordination delivery

Of the 71 reports, 17 described 14 measures that assessed transitional care and care coordination delivery. These measures included three categories: quality of care (n = 6), care engagement (n = 2), and experience with care (n = 6). Each category is described below and assessed for strengths and weaknesses.^{16,18,20,21,23–35}

TABLE 1 Transitions and care coordination measures

Component	Measure	Data source	Strengths ^a	Weaknesses ^a
Identification of the Population				
Needs assessment	<ul style="list-style-type: none"> Johns Hopkins Dementia Care Needs Assessment^{14,15} Unmet Needs Assessment^{16-19,21} 	<ul style="list-style-type: none"> Patient & caregiver report Direct observation 	Person- and family-centered.	Time intensive. Variability between the two measures, but both are based on best practices.
Engagement potential	<ul style="list-style-type: none"> Modified Short Blessed Orientation-Memory-Concentration Test²⁰ 	<ul style="list-style-type: none"> Patient report 	Person- and family-centered. Short.	No clear conceptual model.
Transitional Care & Care Coordination Delivery				
Quality of care	<ul style="list-style-type: none"> The Dementia Management Quality Measures²³ Adherence to Dementia Care Guidelines²⁴ Physician Quality Reporting System²⁵ Palliative Care Treatment Plan Domains^{25,26} Quality of Communication questionnaire²⁶ Symptom Management at the End of Life in Dementia (SM-EOLD)²⁶ 	<ul style="list-style-type: none"> Chart review 	Person- and family-centered.	Time intensive. Variability in conceptual definitions.
Care engagement	<ul style="list-style-type: none"> Goal identification, action steps, & goal attainment^{16,18,20,21} Advance Care Planning completion^{25,26} 	<ul style="list-style-type: none"> Patient & caregiver report Chart review 	Person- and family-centered.	Time intensive. Variability in conceptual definitions.
Experience with care	<ul style="list-style-type: none"> Client Experiences Questionnaire²⁷ Satisfaction with Care at the End of Life in Dementia (SWC-EOLD)^{26,34} Acceptability survey²¹ Care Transitions Measure (CTM-15)³⁵ Preparedness for Caregiving Scale³⁵ Multi-item study-specific survey²⁸⁻³³ 	<ul style="list-style-type: none"> Patient & caregiver report 	Person- and family-centered.	Time intensive. Variability in conceptual definitions.
Transitional Care & Care Coordination Outcomes				
Acute care use, emergency department (ED) use	<ul style="list-style-type: none"> Single item (e.g., ED visit y/n^{16,25,31,43,62,76,77}; total number ED visits^{15,16,28,30,56,64,69,70}) 	<ul style="list-style-type: none"> National health care or insurance Database Caregiver report 	Easily calculated. Limited burden to complete. Person- and family-centered.	Variability in definition and data source.
Hospitalization	<ul style="list-style-type: none"> Single item (e.g., hospitalization y/n^{16,31,34,43,62,64,65,75,78}; total number hospitalizations^{15,16,26-28,30,54,69,70}; number of days hospitalized,^{15,27,30,56}) 	<ul style="list-style-type: none"> National database Caregiver report EHR 	Easily calculated. Limited burden to complete. Person- and family-centered.	Variability in definition and data source.
Rehospitalizations	<ul style="list-style-type: none"> Single item (e.g., rehospitalization y/n^{25,64,65,74}; total number of rehospitalization^{64,65}) 	<ul style="list-style-type: none"> EHR Caregiver report 	Easily calculated. Limited burden to complete. Person- and family-centered.	Variability in definition and data source.
Ambulatory care use	<ul style="list-style-type: none"> Single item (e.g., total clinic visits¹⁵; physician visits^{28,30,31,44,63,76}) 	<ul style="list-style-type: none"> Caregiver report 	Limited burden to complete.	Variability in definition and data source. Not person or family centered.
Home and community-based health service use:				
Medical	<ul style="list-style-type: none"> Single item (e.g., total number of community resources^{24,27,28,50,87}; home health care use^{15,66}; hospice or community-based palliative care use²⁵; care management use²⁸) Skilled nursing facility (e.g., discharged to SNF⁴³; SNF stay y/n, counts, days; respite stay¹⁵) 	<ul style="list-style-type: none"> Caregiver report EHR 	Easily calculated. Limited burden to complete.	Variability in definition and data source. Not person or family centered.

(Continues)

TABLE 1 (Continued)

Component	Measure	Data source	Strengths ^a	Weaknesses ^a
Non-medical supportive services	<ul style="list-style-type: none"> Home care services (e.g., companion, homemaker, personal care assistance)⁴⁴ Social day/adult day care use^{44,87,88}; Respite (e.g., in home respite use^{44,88}; overnight respite care⁴⁴; respite care nights (count)⁴⁴) Combination of services (e.g., meals, homemaker, respite, personal care assistance^{15,46,48,70}) 	<ul style="list-style-type: none"> Caregiver report EHR 	Easily calculated. Limited burden to complete.	Variability in definition and data source. Not person or family centered.
Long-term care use	<ul style="list-style-type: none"> Single item (e.g., long-term care placement^{30,40-42,44,45,48,49,51,53,59,67,68,70,72,73,78,80}; time to long-term care placement^{42,46,47,50,52,53,55,58,60,61,85,89}; length of long-term care placement⁷⁹; change in long-term care facility status⁵⁴; risk of eviction⁵⁴; prevented evictions⁵⁴) Multi-item scale (e.g., anticipated plans to institutionalize)^{57,71} 	<ul style="list-style-type: none"> National health care or insurance database EHR Caregiver report Dementia Care Management System 	Easily calculated. Limited burden to complete.	Variability in definition and data source. Not person or family centered.
Transitions	<ul style="list-style-type: none"> Single item (e.g., time to transition from home)¹⁴ 	<ul style="list-style-type: none"> EHR 	Easily calculated.	Not person or family centered.
Cost	<ul style="list-style-type: none"> Specific costs (e.g., healthcare expenditures⁸¹⁻⁸²; program/care management service cost^{50,82,84}) Total cost^{43,44,48,53,56,70,83,85} 	<ul style="list-style-type: none"> VHA's Decision Support System National health care or insurance database Available data on costs applied to resource use 	Easily calculated.	Variability in definition and data source. Not person or family centered.
Mortality	<ul style="list-style-type: none"> Rate of death^{26,27,40,46,49,60,67,68,86} Time to death or died y/n^{26,34,42,64,65,85} 	<ul style="list-style-type: none"> Clinical Information System National Database Caregiver report 	Easily to calculate. Limited burden to complete.	Variability in definition and data source. Not person and family centered.

Abbreviations: EHR, electronic health record; SNF, skilled nursing facility; VHA, Veterans Health Administration; y/n, yes/no.

^aStrengths and weaknesses include a description of the component related to (1) patient-centeredness, (2) accessibility of data (e.g., ease of use, timeliness, burden), and (3) consistency of measured concept's definition and tool variability.

Six measures across four studies assessed the quality of care coordination or transitional care.²³⁻²⁶ Three measures—(1) dementia management quality measures, (2) adherence to dementia care guidelines, and (3) physician quality reporting system—assessed care based on standards of dementia care when the reports were published,^{23,24,26} while the other three—(4) palliative care treatment plan domains, (5) quality of communication questionnaire, and (6) symptom management at the end of life in dementia—assessed palliative care standards, which are an essential component of dementia care.^{25,26,34} Quality of care is potentially actionable and person- and family-centered; however, there is wide variability in quality definitions and frameworks. None used the DCPR to guide quality assessment. All measures included at least one aspect of transitional care or care coordination, but none comprehensively assessed transitional care and care coordination quality. Further, all measures required time-intensive chart reviews.

Two measurement methods characterized engagement with transitional care and care coordination: measuring goal attainment through identification, action steps, and outcome of goal,^{16,18,20,21} and advance care planning completion.^{25,26} Both measures are explicitly strengths-based and person- and family-centered but can be time intensive

(e.g., number of items, the time it takes to complete the items) and have variable conceptual definitions and frameworks.

Experience with care was the final category to assess care delivery. Four standardized surveys were used: Client Experiences Questionnaire, Satisfaction with Care at the End of Life in Dementia, Care Transitions Measure-15, and the Preparedness for Caregiving Scale,^{26,27,35} which have reported psychometric validity and reliability reported elsewhere.³⁵⁻³⁹ Finally, one study assessed patient and caregiver acceptability of a specific care intervention,²¹ while other studies used program-specific satisfaction questionnaires.²⁸⁻³³ The experience with care is person- and family-centered and actionable. However, there is variability in conceptual definitions and frameworks and can be time intensive to complete.

4.3 | Transitional care and care coordination outcomes

Among the 71 reports, 60 included 16 measures of transitional care and care coordination outcomes related to the person living with dementia and caregivers (see Table 1). Care transitions

and care coordination outcomes measures primarily focus on health-care use ($n = 48$; e.g., acute care, post-acute care, ambulatory care, long-term care)^{15,16,24,25,27,28,30,31,34,40–80} and cost outcomes ($n = 12$).^{43,44,48,50,53,56,70,81–85} Mortality was also a common outcome measure in care transitions and care coordination studies ($n = 14$).^{26,27,34,40,42,46,49,60,64,65,67,68,85,86} Below each type is described.

Health-care resource use measures ranged from single dichotomous measures of events (emergency department visit, hospitalization, rehospitalization; yes/no),^{16,25,31,34,43,62,64,65,74–78} to total counts of events over time^{15,16,25–28,30,54,56,64,65,69,70} and number of days hospitalized.^{15,27,30,56} Almost all health-care use data came from health-care systems or insurers (e.g., Centers for Medicare and Medicaid Services Medicare claims data) but self-reported data via interviews with caregivers were also commonly used, with cross-referencing health-care system data for completeness and accuracy.^{64,65}

Post-acute care use fell into three categories: ambulatory care use, skilled nursing facility stays (short-stay rehabilitation), and home and community-based service use. These data were often caregiver-reported and/or an electronic health record (EHR) review. Ambulatory care use measures services such as visits to health clinics, physician offices, or specialist visits.^{15,28,30,31,44,63,76} While home and community-based care included receiving services (at least one time or total counts of home and community-based service use) and ranged from health-care services (e.g., traditional home health care services or episodes,^{15,66} hospice or community-based palliative care use,²⁵ care management use²⁸) to transportation services, social or adult day care, congregate meals, and other non-medical community services.^{24,27,28,50,87,88} Skilled nursing facility use as a step down from the hospital back to the community for older adults living with dementia differed from long-term care placement (e.g., nursing home) and was a common measure of service use (e.g., discharged to a skilled nursing facility⁴³ or respite stay¹⁵).

Finally, the transition to long-term care as an outcome of transitional care and care coordination studies targeting keeping the person living with dementia in the community was common. This outcome measure was found in claims data (e.g., Medicare, Veterans Health Administration), EHR, caregiver self-reports, and other dementia-specific datasets. This outcome was used in a variety of ways, but most often as a dichotomous, “placement” or “no placement.”^{30,40–42,44,45,48,49,51,53,59,67,68,70,72,73,78,80,85,89}

The cost of resource use was another common outcome measure that accompanies resource use data. There was wide variability in how cost was measured from actual costs available in the claims data (e.g., Medicare claims) to an average cost assigned based on available data reported for a given year (e.g., Healthcare Cost and Utilization Project⁹⁰). Often interventions targeting transitions in care and care coordination examine costs of the intervention as well as the cost of the acute and post-acute care services.^{27,43,44,48,50,53,56,70,81–85}

Mortality was frequently measured in studies that explored transitional care and care coordination. Twelve reports measured rate of death or time to death via EHR, caregiver report, or a national

registry.^{26,27,34,40,42,46,49,60,64,65,67,68,85,86} Mortality was sometimes used to measure differences in survival among persons living with dementia who received an evidence-based intervention versus a control or comparison group.^{42,68,85,86} Some studies combined mortality with other outcomes such as hospitalization.^{64,65}

While examining costs and mortality are not person- or family-centered outcomes, there is consistency in how costs are calculated (e.g., actual claims data, cost to implement an intervention) and mortality ascertained. Health-care use, costs, and mortality data were also accessible through various data sources though they may vary in reliability (from self-report by caregivers to EHR to claims data). Examining a program's cost savings and expenditures are important measures to determine whether replication is economically feasible.

5 | DISCUSSION

Overall, this integrative review identified 71 reports that described measures of transitional care and care coordination in three categories: (1) identification of the population, (2) transitional care and care coordination delivery, and (3) transitional care and care coordination outcomes. Dementia transitions and care coordination measures are varied across research studies and focus heavily on outcomes, specifically health-care resource use and cost, rather than the elements of transitional care or care coordination.

A strength of this study is that it provides a view of what has been measured to date in the dementia care transitions and care coordination space. This overview of the measurement landscape allows researchers to determine the strengths and weaknesses of current measurements and identify opportunities for growth. This review revealed that of the practice recommendations for transitions in care outlined in Hirschman and Hodgson⁹—preparation and education about common transitions; timely communication between, across, and within settings; evaluation of preferences and goals; interprofessional team collaboration; and initiating use of evidence-based models—none were addressed entirely, and most were missing completely. While eight reports examined needs prior to the start of an evidence-based intervention to improve transitions,^{14–21} which may be one component of preparation, only one report evaluated preparation and the transitions experience explicitly and this was done after the transition occurred.³⁵ One measure assessed communication but this was primarily focused on communication between provider and patient or caregiver and not on communication between providers and care settings.²⁶ No reports used measures for preferences and goals. Therefore, there is a need to identify and evaluate measures that focus on preferences and goals across the illness trajectory that are important in daily living (e.g., preferences for everyday living⁹¹) and may influence transitions and care coordination decisions. Exploration of measures used within the Institute for Healthcare Improvement 4 Ms framework for age-friendly care may yield promising measures, specifically in the “What Matters” category.⁹² No identified measures assessed interprofessional teams, though a substitute might be quality of care or satisfaction.^{16,18,20,21,23–33,35}

Importantly, no comprehensive, standardized tools are used to measure the full spectrum of care coordination and transitional care delivery across different studies. All the measures of transitional care and care coordination delivery included in this review were study-specific or measured one aspect of transitional care and care coordination, such as quality of care, care engagement, or satisfaction with care. Investing time in evaluating the implementation of evidence-based models, which includes identifying measurement of processes and outcomes, is needed.

Most striking was the focus on health-care resource use and cost outcomes to measure care transitions and care coordination. There were 60 out of 71 studies of transitional care or care coordination for persons living with dementia that used health-care events and costs as a primary measure of outcomes. While reducing avoidable emergency department visits and hospitalizations is inherently person- and family-centered, measures of costs and mortality are not.⁹³ Overall, these data are easily accessible and can limit the burden to collect, and generally, the measures are consistent across studies. Where there is variability in timing of events being measured (e.g., 30–90–180–365 days post-hospital discharge). Most of the available measures to identify the population and evaluate transitions in care and care coordination services are person- and family-centered; however, their reach is limited as noted by the small number of studies reporting use of these measures. Data required to complete these forms are primarily self-report from both persons living with dementia and their caregivers, which may not always be accessible or feasible for large cohorts. Specifically, the measures used to examine care coordination and transitional care delivery while they have actionable items, there is wide variability in conceptual definitions and reported use in the literature. Finding ways to better identify the population in need of transitional care or care coordination and evaluate the services they receive is essential.

5.1 | Limitations

While we provided a broad, expansive review of the literature it is important to highlight that our findings are limited by the search terms selected, sources searched, and eligibility criteria. The measures identified in this review represent the broad approach to try to capture measures related to transitions in care and care coordination for persons living with dementia and their family caregivers. We did not assess each individual study for positive or negative outcomes but rather identified their use of available measures and qualities of the measures: actionability, nature (e.g., person- and family-centered), included strengths-based perspectives, represented across studies, and if there was a high or low burden of completion. It is also possible that not enough time has transpired since the original publication of the DCPR to translate them into practice and provide effective transitional care and care coordination that can align with measures. Finally, it is possible that measures used to capture some of the elements of transitional care and care coordination have not yet been adapted or tested with persons living with dementia.

There is an opportunity to develop new tools to measure preparation and education about common transitions; timely communication between, across, and within settings; evaluation of preferences and goals; interprofessional team collaboration; and initiating use of evidence-based models. The use implementation science as a structure for measuring the process of transitional and care management should be considered in future research. The adaptation of existing tools not yet tested with persons living with dementia and their family caregivers as well as the evaluation of specific care transitions or care coordination intervention elements with this population are needed.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest. Author disclosures are available in the [supporting information](#).

PATIENT CONSENT STATEMENT

Not applicable.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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