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REVIEW ARTICLE

Dementia care navigation: Building toward a common definition, key principles, and outcomes

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Abstract

INTRODUCTION: As the complexity of medical treatments and patient care systems have increased, the concept of patient navigation is growing in both popularity and breadth of application. Patient navigators are trained personnel whose role is not to provide clinical care, but to partner with patients to help them identify their needs and goals and then overcome modifiable patient-, provider-, and systems-level barriers. Due to its high incidence, duration, and medical–social complexity, dementia is an ideal candidate for a patient-centric health care delivery model such as care navigation.

METHODS: The Alzheimer's Association formed an expert workgroup of researchers in the field of dementia care navigation to identify evidence-based guidelines.

RESULTS: Recognizing the unique and challenging needs of persons living with dementia and their care partners, several U.S. dementia care navigation programs have been developed and assessed in recent years. Collectively these programs demonstrate that persons living with dementia and their care partners benefit from dementia care navigation. Improved care system outcomes for the person living with dementia include reduced emergency department visits, lower hospital readmissions, fewer days hospitalized, and shorter delays in long-term care placement. Well-being is also increased, as there is decreased depression, illness, strain, embarrassment, and behavioral symptoms and increased self-reported quality of life. For care partners, dementia navigation resulted in decreased depression, burden, and unmet needs.

DISCUSSION: This article presents principles of dementia care navigation to inform existing and emerging dementia care navigation programs.

KEYWORDS
care navigation, care planning, dementia, patient navigators

Highlights

- Several U.S. dementia care navigation programs have demonstrated outcomes for persons living with dementia, care partners, and health systems.
- The Alzheimer's Association formed an expert workgroup of researchers in the field of dementia care navigation to create a shared definition and identify evidence-based guidelines or principles.
- These outlined principles of dementia care navigation can inform existing and emerging dementia care navigation programs.

1 | INTRODUCTION

As the complexity of medical treatments and patient care systems has increased, the concept of patient navigation is growing in both popularity and breadth of application. Patient navigators are trained personnel whose role is to partner with patients to help them identify their needs and goals and then overcome modifiable patient-, provider-, and systems-level barriers.[1,2] Navigators can be nurses, social workers, lay health workers, or peers working individually or in various team and supervisory arrangements. Navigation activities include disease education, health system education, assistance with insurance and public benefits, care coordination and communication, advance care planning, referral to community resources, arranging transportation, medication monitoring, emotional and cultural support, screening for safety needs, non-pharmacological behavior symptom management, and others. Since its beginnings in oncology in the 1980s, the navigator approach is being applied to an increasing variety of chronic diseases, including diabetes, HIV/AIDS, cardiovascular disease, kidney disease, smoking, multiple morbidity, and dementia.[2]

Due to its high incidence, duration, and medical–social complexity, dementia is an ideal candidate for a patient-centric health care delivery model such as care navigation.[3] Dementia affects more than 6 million persons in the United States, and more than 12 million are expected to be affected by 2050.[4] The average time from diagnosis to death is 5 years,[5] during which gradual or episodic declines create a continuously changing and highly individualized set of issues and needs for persons living with dementia (PLWD) and their care partners. Medical care quality for dementia tends to be poor, with studies showing that patients receive half or less of the recommended care components relating to treatment, education/support, assessment, and safety.[6,7] Over the last two decades, significant efforts have been made to encourage primary care physicians to detect and diagnose dementia and experts highlight the many benefits of an early diagnosis including participation in clinical trials, access to caregiver resources, and support and the opportunity to make plans for care and end of life.[8] The availability of effective treatments and biomarker-based tests will further encourage diagnosis but barriers to early diagnosis remain even as health care providers recognize the need for more-effective support systems for themselves and their patients receiving a diagnosis.[9]

Financial, legal, health, and insurance services can be intimidating generally; navigating these services in the context of dementia is even more complicated and frustrating. Community-based organizations offer resources for addressing these barriers, but they are generally underutilized. Among unpaid family and community-dwelling care partners generally, one study found that only a fourth took advantage of supportive services.[10] Even once referrals are made, managing appointments, medications, and other treatments for PLWD who often have multi-morbidity and polypharmacy can be a significant burden. Primary care providers have limited capacity and expertise to assist in all the areas of need associated with dementia,[1] and especially traditionally non-medical activities such as counseling, education, and referrals to community-based organizations.[11,12]

Given these complexities, dementia care navigation is as important for the care partner as it is for the PLWD. In the United States alone, more than 11 million family members and friends provide informal care for PLWD.[4] Many care partners experience burden and resultant declines in their own health, such as depression, stress, and increased risk of disease and mortality.[13–17] Widespread public fear and stigma around dementia contribute to social isolation among PLWD and their care partners. Educational materials about dementia abound, and the science, care, and treatment of dementia are constantly evolving. Together, this can create an overwhelming level of information overload, especially when care partners themselves are often elderly, have their own illnesses, or have competing work and family responsibilities.

1.1 | Dementia care navigation programs

Recognizing the unique and challenging needs of PLWD and their care partners, several U.S. dementia care navigation programs have been developed and assessed in recent years. These programs operate within or in direct collaboration with a health system. The Agency for Healthcare Research Quality defines a health system as including at least one hospital and one group of physicians providing comprehensive care and are connected to each other and the hospital under joint ownership or management.[18] The programs reviewed include (1) Care Ecosystem[19,20]; (2) the Benjamin Rose Institute (BRI) Care Consultation[21] and the related Partners in Dementia Care for veterans with dementia (PDI)[22,23] and Cleveland Alzheimer's Managed Care Demonstration[21,24]; (3) Maximizing Independence at Home (Mind at Home),[25] a home-based program delivered through a community-based aging service provider; (4) the Alzheimer's and Dementia Care Program (ADCP),[26,27] a health care system–based model; and (5) Collaborative Care for Older Adults with Alzheimer's Disease in Primary Care,[28] a primary care–based model focused primarily on behavioral and psychological symptoms of dementia.

Collectively, these programs demonstrate that PLWD and their care partners benefit from dementia care navigation. Improved care system outcomes for the PLWD include reduced emergency department visits, lower hospital readmissions, fewer days hospitalized, and shorter delays in long-term care placement.[20,25,26] Well-being is also increased, as there is decreased depression, illness, strain, embarrassment, and behavioral symptoms[23,28] and increased self-reported quality of life.[20,25] For care partners, dementia navigation resulted in decreased depression,[20,28] burden,[20] and unmet needs.[22] Providing dementia care navigation services may be cost neutral for health systems,[26,29] although few studies have included cost analysis or compared costs between programs.

There are number of differences between these programs, however, and as interest in dementia care navigation flourishes, it is important to define what exactly is meant by the term. Although all of the existing programs focus on providing comprehensive, individualized guidance and support to PWLD and their care partners, and all are designed to supplement and enhance (but not replace) existing medical care, they differ with regard to payment structures, navigator training level and background, supervisory structures, settings (academic and non-academic health care– or community-based organization), program evaluation methods, and other aspects. These differences allow for customized implementation within health systems and community organizations based on patient, caregiver, and community needs. Clearly, both users and funders need to know what to expect from such programs.[2] In the absence of common standards, wide variability and potential misunderstandings about what constitutes a dementia care patient navigation program are likely to arise.[30]

In furtherance of this goal, the Alzheimer's Association identified a panel of experts who met in person at the Alzheimer's Association Chicago headquarters in March of 2020. The goals of the meeting were to create a definition of care navigation as it applies to dementia, draft a set of key principles, and identify appropriate process and outcome measures to assess and refine these service components through research and program evaluation. The intent of this article is to provide principles that set a standard for the delivery of dementia care navigation within or in collaboration with health systems.

RESEARCH IN CONTEXT

1. **Systematic review**: Five U.S. dementia care navigation programs developed and assessed in recent years were identified and reviewed. Collectively these programs demonstrate benefits for persons living with dementia (PLWD; such as increased well-being and reduced emergency department visits), as well as their care partners (such as decreased depression and unmet needs).
2. **Interpretation**: The Alzheimer's Association formed an expert workgroup of researchers in dementia care navigation to create a definition of care navigation for dementia, draft a set of key principles, and identify appropriate process and outcome measures to assess and refine service components through research and program evaluation. The resulting principles of dementia care navigation outlined in this article provide guidance for other dementia care navigation programs.
3. **Future directions**: Given the current environment with potential treatments for Alzheimer's as well as legislative and regulatory efforts around alternate payment models for dementia, we believe it is critical to provide evidence-based guidance for health systems to successfully implement dementia care navigation.

1.2 | Toward a definition of dementia care navigation

Several existing definitions of patient navigation were reviewed, including those by Freeman,[3,31] the American Medical Association, the American College of Surgeons, the Joint Position Statement of the Oncology Nursing Society, the Association of Oncology Social Work, and the National Association of Social Workers. As applied to PLWD and their care partners, these definitions were seen as overly focused on the medical components of care, being a better fit for chronic conditions with established medical treatments, such as cancer and diabetes. Existing definitions were also viewed as lacking sufficient emphasis on personalization, empowerment, and support over time. The working definition of dementia care navigation developed by the expert workgroup encompasses these points in the following way:

> Dementia Care Navigation is a program that provides tailored, strengths-based support to persons living with dementia and their care partners across the illness continuum and settings to mitigate the impact of dementia through collaborative problem solving and coaching.

Judge and colleagues[32] list the following as key aspects of using a strengths-based approach including facilitating participation from both care partners in the intervention process; focusing on identifying caregivers (CG's) and individuals with dementia (IWD's) individual and collective strengths as care partners, and; building on what was currently working for dyads while learning techniques to compensate for cognitive and functional changes due to memory loss.

1.3 | Toward a set of key principles of dementia care navigation

Freeman's Principles of Navigation[33] once again served as an inspiration for these discussions, along with the collective expertise of the work group and the peer-reviewed literature on dementia care generally and dementia-care navigation specifically. The unique situation of persons with dementia and their care partners required modifications to Freeman's principles, specifically with respect to emphasizing patient-centeredness, the reduction of disparities, continuity of care across settings, and emphasizing strengths-based support over direct coordination. For each principle, examples of elements from the evidence-based programs were outlined (see Table 1).

1. The goal of every aspect of patient navigation is to be person- and family-centered in order to ensure collaboration and enhance engagement.

   In patient-centered processes, the particular needs and goals of the individual receiving assistance guides care. Patients and their care partners are instrumental partners in the process of clarifying needs and goals specific to the broad range of challenges that they may experience including medical, social, financial, emotional, and spiritual. The dose, or frequency and intensity of support, is then adapted to the patient's and caregiver's needs and readiness for engagement. Studies demonstrate that an important factor in the level of burden experienced by a caregiver is how competent the caregiver feels in the role,[34] and that greater caregiver knowledge is associated with higher care quality.[7] In addition, individualized assessments match to level of need and include person living with dementia and caregiver components.
2. Dementia care navigation is culturally responsive and addresses disparities in access to health care and support services.

   It includes cultural sensitivity and knowledge of the local community. Accomplishing this component requires cultural sensitivity and intimate knowledge of the local community. Partnerships with local organizations are a key aspect of promoting health equity.[35] All of the existing programs collaborate with, are based in, and/or refer to community-based services and organizations that are representative of the populations being served.
3. There are well-defined roles and responsibilities for all members of the dementia care navigation team.

   The review found wide variation in the educational backgrounds and overall structure of the navigation teams, but in each model, clinicians were a part of the teams and there were well-defined roles and responsibilities for all team members. All models follow a manualized care coordination protocol that provides clear position descriptions, competencies, and role expectations.
4. Dementia care navigation addresses barriers relating to medical, legal, financial, emotional, and other domains facing the person living with dementia and their care partners.

   All of the existing programs have a multicomponent focus, screening for and responding to unmet needs relating to medical, legal, social, emotional, and financial needs. Reponses to unmet needs in these areas can include referral to community groups and offering resources and help in the form of support groups, counseling, adult day and other respite care, education/training, help with Medicare/Medicaid and other benefit enrollment, legal assistance, safety evaluations, housing advocacy, vouchers, behavior management interventions, and medication management.
5. Dementia care navigation provides coaching, education, and coordination in a manner that is empowering, solution-focused, and strengths-based.

   Different programs take a more or less hands on approach, but all models focus on education and skills building in order to increase the independence, confidence, and resources of the PLWD and their care partner.
6. Due to the progressive cognitive and functional declines that characterize dementia, and in recognition of the important role of care partners, dementia care navigation focuses on the family unit as defined by the patient.

   When a patient does not have a care partner, dementia care navigation facilitates connection to appropriate community-based organizations. All of the models included in this review are based on a family-centric, whole-person approach to health. Although the primary target is the PLWD and their care partner, other family and friend care partners are involved as available and beneficial. When a PLWD does not have an identifiable care partner, dementia care navigation facilitates connection to appropriate community-based organizations. The PLWD's and care partners' capabilities and unmet needs are reassessed continuously over time. Most models offer at least monthly contacts, with higher or lower frequency dependent on the clients' needs and wishes. Roughly three-fourths of contacts are by phone, but they also occur over email, in person, and through video conferencing. To monitor changing needs, reassessments are conducted at every contact, but some models also include a full reassessment at stipulated intervals.
7. Dementia care navigation processes and protocols are evidence-based.

   All five of the models reviewed here demonstrate effective outcomes, and there is ongoing research being conducted on their protocols. In addition to this ongoing research, the navigation protocols were designed from their onset to be responsive to guideline-based quality indicators for dementia. Some models include automatically generated reports of fidelity to protocols, offer electronic tracking systems that provide continuous quality feedback to the entire team, and/or conduct consumer satisfaction and other client evaluation tools on a pre-established schedule that are then reviewed at team or supervisory meetings.

2 | PROCESS AND OUTCOME MEASURES

Process and outcome measures are essential to advancing the goals of dementia care navigation, both in terms of contributing to the peer-reviewed literature and to enable ongoing quality control and monitoring of the navigation delivery process. Existing dementia

TABLE 1 Elements of evidence-based dementia care navigation programs.

	Contact Structure	Published findings	P1. Person/family centered	P2. Reduce disparities	P3. Well-defined roles	P4. Addresses the continuum of barriers	P5. Provides coaching	P6. Focus on family unit	P7. Evidence-based protocols
1. Care ecosystem Collaborative care model delivered remotely by Care Team Navigators (CTNs) who are trained, supported, and supervised by a clinical team with dementia expertise in nursing, pharmacy, and social work. Supplements usual care in health system by providing information, support, and links to community-based services.	Telephone, e-mail and mail. Aim to identify and help address immediate needs first. Then build rapport while completing comprehensive care plan in 3 months after enrollment. Provide personalized support, information, and resources using care protocols. Monthly follow-up by phone, adjusted for CG needs and preferences. Mean # of calls: 15.3 per year, plus emails. Caseload size in controlled trial ranged from 35–90. Target caseload size in implementation projects is 75	Randomized controlled trial (RCT) of 780 dyads rural and urban dwelling participants across 3 states. Reported results after 12-month enrollment Improved quality of life (QOL) of person living with dementia (PLWD), reduced PLWD ER visits, decreased CG burden and depression. Qualitative interviews found satisfaction with CTNs and identified barriers (burn out, progressive nature of disease, coordination With PCP, identifying resources for low-income dyads, non -English speakers, rural) Facilitators were working closely with CTN, emotional support, tailoring, and coordinating with clinical team.	Comprehensive care planning process allows CTN to tailor information, resources, and support to match the resources, needs, and preferences of the dyad.	Offered in English, Spanish, and Cantonese.	CTNs are unlicensed but trained (40 hours). Care delivery is guided by protocols. CTNs are supported and supervised by a clinical team with dementia expertise in nursing, pharmacy, and social work. Weekly case reviews, as needed case consultation, and ongoing supervision.	Protocols guide comprehensive needs assessment and care planning process. CTNs use vetted information and referrals to provide guidance and help address medical, legal, social, and financial needs.	CTN training program emphasizes active listening, asking questions to understand goals, and using a collaborative approach to identify possible strategies or solutions. CTNs provide ongoing follow-up to monitor for changes, needs, barriers, and to provide support.	Primary CG is identified to act as main contact for program and to complete evaluation surveys. The CTN may contact and coordinate care with the PLWD and other family/friends or professionals involved in the person's care	NPI (Neuropsychiatric Inventory) for behavior assessment DICE (Describe, Investigate, Create a plan, Evaluate) framework for behavior management Beers criteria for medication reviews PHQ-9 (Patient Health Questionnaire) to screen for caregiver depression Comprehensive care plans meet 7 of the quality measures modified from the *2015 American Academy of Neurology Institute (AANI) and American Psychiatric Association (APA) Dementia Management Quality Measurement Set*

(Continues)

TABLE 1 (Continued)

	Contact Structure	Published findings	P1. Person/family centered	P2. Reduce disparities	P3. Well-defined roles	P4. Addresses the continuum of barriers	P5. Provides coaching	P6. Focus on family unit	P7. Evidence-based protocols
2. **BRI care consultation including partners in dementia care (10 completed studies)**	Phone, email, and mail. At least monthly contacts, most by phone (80%), but also mail/email (16%) and in person (4%). Initial assessment during first 4 months; re-assessment every 6 months. Ongoing contacts revisiting of assessment questions as needed. Standard protocol with personalized content	10 research studies, 4 of which were randomized control trial (RCTs). Tested efficacy, effectiveness, and feasibility for scaling in communities. 1 multisite comparative effectiveness study underway. Decreased CG: unmet needs, depression, strain, isolation and increased support service use and family/friend help. Decreased PWD: unmet needs, depression, illness, strain embarrassment, emergency department (ED) visits, hospital readmissions. Increased community service use and satisfaction with family support.	Serves both the PLWD and caregiver, when applicable. Consumer directed; follows consumer preferences.		75-125 families per Care Consultant; BA or MA degree (SW, RN, other) Delivered by a single health care or community organization. Or the partnership version is delivered by a healthcare and community organizations working in tandem. There are 40-50 licensed healthcare or community organizations currently delivering the program.	Ongoing program with a minimum of 3-months of use. Responds to change in illness and caregiving. Attention to holistic range of potential medical and non-medical problems and concerns.	(1) Access, coordinate, monitor healthcare and community services, (2) Promote optimal family/friend involvement in care, (3) Coaching and emotional support, 4) Quality vetted educational resources to empower consumers.	Uses a holistic, family-centered approach. Works with both the person living with dementia and primary family or friend caregivers, when there are caregivers. Involves other family and friends in Action Steps.	Automated administrative and fidelity reports are generated via the customized software platform used by Care Consultants to deliver the program.Evaluation tools.

(Continues)

TABLE 1 (Continued)

	Contact Structure	Published findings	P1. Person/family centered	P2. Reduce disparities	P3. Well-defined roles	P4. Addresses the continuum of barriers	P5. Provides coaching	P6. Focus on family unit	P7. Evidence-based protocols
3. **UCLA (ADC) Alzheimer and dementia care** Health care system based with community organization partnerships Goals: maximize PLWD independence, and dignity Minimize CG strain Reduce unnecessary costs	In-person/video initially annually Telephone/video/in-person as needed thereafter. Calls at least quarterly for low acuity dyads. In person/video reassessment annually.	Compared to matched Medicare cohort. Found avoided long term care (LTC) longer and had lower costs, but evened out after including cost of intervention. (slides have info too)12% less hospitalization20% less ED visits 26% less hospital days 60% increase in Hospice in last 6 mon Total Medicare costs saved: $2404 Nursing home placement: 40% less.	Red/Yellow/Green acuity levels. Individualized. PWD and CG support-DYAD	Referred to local orgs. Offers vouchers to help with financial barriers.	NPs are the managers, with caseloads of up to 250-300 each!Each DCS (Dementia Care Specialist) has a non-licensed assistant and together they manage up to 300 patient continuity panel	Care is a long journey. Medical, support groups, counseling, adult day care, education/training, benefits enrollment, Medicare/Medicaid help, financial/legal help, housing advocacy Acuity levels (Red, yellow, green) described in the slides. Green is a standardized script	Skills building and referrals.	The DCS works with not only the PLWD and their family caregiver, but also extended family and friends that may be involved in the PLWD's care. Connections are made with community based organizations for additional support, education and resources.	Patient tracking and program enrollment managed by care coordination modules in the electronic health records (EHR). Tasks and reminders ensure follow up and delegation of tasks within the team. Identifying active enrollment allows others within the healthcare system to identify the Alzheimer's Disease Center (ADC) involvement and contact the program if needed.

(Continues)

TABLE 1 (Continued)

	Contact Structure	Published findings	P1. Person/family centered	P2. Reduce disparities	P3. Well-defined roles	P4. Addresses the continuum of barriers	P5. Provides coaching	P6. Focus on family unit	P7. Evidence-based protocols
4. Care Consultation **(CC) for older adults with AD in primary care**	In person initially, then twice a month, then monthly. Half in person and half telephone. Ave 14.4 contacts over 12 months. Assessments done at each visit. At least monthly.	Improvements in quality of care (QOC) and behavioral and psychological symptoms of dementia (BPSD) among PWD and CG. Improved in depression among CG. No diff in hospital use, etc.	Focused on PLWD and caregiver.	Referred to the local Alzheimer's Association and provided assisted referral to other community based services and supports. "collaboration with community services"	2 managers, with weekly support from geriatrician, psychologist, neuro person. In practical implementation of the model over the past 10 years, have moved to care coordinator assistants and social worker teams supported by geriatrician. Social worker is integrated with local Area Agency on Aging	Includes legal financial, but doesn't say much about continuum of resource needs over time. "longitudinal co-management over years" In practical implementation of the model over the past 10 years, team approaches care as a journey with a tailored approach to each patient's resources and stage of illness which are continually changing. Care coordinators and social workers are not limited to medical care issues alone	Not clear The original intervention included brief problem solving psychotherapy for depression and behavioral activation. In practical application of the model over the past 10 years, the team relies more often on education, coaching, and behavioral activation based on current problems and barriers	Focus has been primarily on dyad but frequently the patient relies on multiple family caregivers or a changing pattern of family caregivers.	Electronic tracking system provides feedback to entire team. In practical implementation of the model over the past 10 years, team relies on specific measures of outcomes including PHQ-9 and the Healthy Aging Brain Center Monitor- a comprehensive measure of stressor and mood coupled with team actions based on patient and/or caregiver scores

(Continues)

TABLE 1 (Continued)

	Contact Structure	Published findings	P1. Person/family centered	P2. Reduce disparities	P3. Well-defined roles	P4. Addresses the continuum of barriers	P5. Provides coaching	P6. Focus on family unit	P7. Evidence-based protocols
5. **Maximizing Independence (MIND) at Home** Designed for low-cost, high-touch comprehensive home-based care coordination that includes a broad assessment, and efficient individualized care planning and collaborative care coordination RCT showed delay in time to transition from home. Reduction in unmet needs for safety and legal/advance directive domains, and self-report QOL. Demonstration project showed reduced Medicaid total spending compared to comparison group. Preliminary results from operational pilot in Medicaid plan	In person home-based evaluation, at least monthly calls and emails. Other in person as needed. Averaged 2 contacts per month, mostly with the caregiver. 72% were phone based, but believe the initial home visit was essential. For first 6 months, encounters every 30 days or less. Monitoring and revision of care plan for at least 6 months. Optimal dose for outcomes at least 12 months.	Pilot RCT. Reduced time to transition from home, safety and legal unmet needs, and self-reported QOL. CMS HCIA demonstration project. Reductions in Medicaid expenditures of dually-eligible participants Compared to matched comparison group. Savings from inpatient and long-term nursing home use. 5-year Medicaid savings are estimated at a 1.12-fold return on investment	Comprehensive in home initial evaluation assessing 13 care domains. Development and implementation of care plan tailored to PLWD and CP based on clinician assessed needs and PLWD, CP care goals and priorities.	All local referral resources. Care team cultural sensitivity training initial and on-going continuing education. Targeting lower income program participants (dual eligible, Medicaid only) Staff selection based on local community.	Core Care Team includes non-clinical community workers, a nurse, and, geriatric psychiatrist. Additional team member configurations of MIND may include SW, OT, PT, pharmacist, geriatrician, behavioral health specialist, others; manualized care coordination protocol; one-month training of coordinator Standardized training for all team members and MCC (8 online modules, 2-day intensive, observed field practicum with trained staff). Clear job descriptions(competencies and role expectations	Community-based with goal of keeping the person at home, sustaining quality of life, reducing unnecessary acute health care utilization, reducing caregiver burden. Systematically assesses and addresses 13 major domains of dementia related care: Cognition, behavior, medical care, safety, meaningful activities, health care financing, ADLS and daily living, legal issues, advanced care, caregiver education and skills, caregiver physical health and mental health, caregiver daily living, caregiver legal considerations, caregiver informal support.	High touch service that includes coaching caregivers on dementia education and skill building, referral and linkage to services; symptoms screening, and needs reassessment over time, care monitoring, direct care coordination. But pretty hands on – attending appointments, pricing medical equipment, and so on.	Based on a family-centric, whole person approach to health. Primarily targets PLWD and care partner. Also involves other family care partners as available	Manualized needs assessment (Johns Hopkins Dementia Care Needs Assessment 2.0) and MIND care coordination protocol that includes interventions based on best research evidence and up to date clinical practice recommendations. Protocols for use of EMR and cloud-based custom management software to track care delivery, fidelity, and outcomes. Tele collaborative software

navigation intervention outcome studies have included a wide range of patient (quality of life, unmet safety and legal needs, depression, strain, embarrassment, behavioral and psychological symptoms of dementia (BPSD)), caregiver (quality of life, unmet safety and legal needs, depression, stress and strain, family/friend help, satisfaction with family support), process (number of navigator contacts, number of referrals to community-based organizations), service use outcome (emergency department, hospital use, hospital days, hospital readmissions, community service, time to transition to residential care, increasing hospice use in last 6 months, nursing home placement), and cost measures. Although the results have been positive, our expert panel expressed frustration that traditional outcome measures have a limited capacity to capture the true impact of dementia care navigation. These frustrations mirror a general growing interest in the field of dementia care for identifying measurable outcomes more meaningful to care recipients.[36] In addition to capturing a fuller and more accurate spectrum of the benefits to PLWD and their care partners, a more person-centered research approach recognizes the important role that PLWD and their care partners can have in the development and design of research questions and studies.[37] Ultimately research that includes variables of meaning to the recipients of dementia care navigation will be of greater interest to PLWD and their care partners, potentially leading to both a greater general awareness of the existence and value of navigation, as well as increasing willingness to participate in future studies.

New, more person-centered measurement approaches attempt to capture the positive characteristics and capacities of persons that enable continued well-being.[38] The concept of measuring "social health," for example, includes the degree to which one is able to fulfill one's obligations and potential, maintain as much independence as desired, and participate in meaningful activities (i.e., activities that are linked to self-esteem and identify and not just a way to pass time).[39,40] Cox et al.[41] identify five core values that should be reflected in dementia-outcome measures, namely: maximizing personal control; enabling choice; respecting dignity; preserving continuity; and promoting equity.[41] Gwyther[42] emphasizes measures that take into account one's sense of control, inclusion, reciprocity, meaningful activities, feeling safe and secure, maintaining self-esteem, maximizing physical well-being, and having services that match perceived needs.

Within the context of dementia care navigation, measures of positive well-being could include maintenance of specific activities of daily living or the frequency of engaging in social or work activities that are meaningful or a part of the identity of the PLWD, the care partner, or the two as a dyad. It is important that measures need to reflect the progressive and degenerative nature of the disease, while still focusing on positive well-being and engagement. These activities could be unique to each research participant and identified at the beginning of the study, with maintenance or increases in the frequency or satisfaction of engagement in their unique chosen activity as the measurable outcome. Traditional measures of stress, strain, and isolation could be balanced with measures of a sense of mastery or self-efficacy in navigating the legal or medical systems, the frequency of enjoying social time with family and friends, the awareness of services and community supports available to them, and a sense of having a safety net and knowledge and skills to meet whatever challenges tomorrow brings.

In addition to more traditional process measures, such as the number of contacts with the navigator or the number of community-based referrals that patients receive and/or contact, person-centered process measures might include the degree to which they felt heard by the navigator, or the frequency with which they begin to initiate and take the lead on identifying issues or solutions.

3 | CONCLUSION/FUTURE DIRECTIONS

Dementia care navigation has proven benefits for the PLWD, their care partners, and health care systems. When individuals and their care partners are provided with appropriate support and community resources, the outcomes are beneficial to all, including increased self-reported quality of life, decreased burden, and reduced emergency department visits, to name a few. These principles offer guidance for health systems to implement dementia care navigation; however, further research in real life settings is needed. The advent of effective treatments for Alzheimer's disease is quite likely to provide significant impetus for primary care practices and health systems to deliver dementia care navigation, in part, as a way to support primary care providers as they face the influx of patients demanding access to treatment and quality care. This increased adoption will afford ongoing opportunities for further evaluation and research.

There is also the need to build capacity across health systems to better serve the needs of those living with dementia and their caregivers. Part of building capacity will include the dissemination of toolkits and resources to support health systems in creating and delivering dementia care navigation. Because the landscape in dementia treatment and care will continue to change, the field will need to adapt. Borrowing from other disease states, one opportunity to support the adoption of dementia care navigation programs would be the creation of a national Dementia Care Navigation Round Table that would include providers, payors, and researchers who would regularly meet to identify challenges, share best practices, and promote ongoing research.

However, creating a health system environment that will support dementia care navigation remains challenging due in part to the current payor model. Resourcing a dementia care navigation program requires the health system to make an investment upfront—yet any savings that occur are unfortunately not reflected in the health system's bottom line. Therefore, in addition to shared definitions and standards, we also need to consider policies that would include alternative payment models and take the burden off health systems as well as outcome measures specific to dementia care navigation.

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The authors have nothing to report.

CONFLICT OF INTEREST STATEMENT

B.K.: Travel expenses for the Dementia Care Navigation workgroup meeting were provided by the Alzheimer's Association. **C.C.**: Travel expenses for the Dementia Care Navigation workgroup meeting were provided by the Alzheimer's Association. Member of UCLA D-CARE Advisory Board. **D.B.**: Travel expenses for the Dementia Care Navigation workgroup meeting were provided by the Alzheimer's Association. Licensing fee from organizations to Benjamin Rose Institute (BRI) on Aging for permission and all materials and training to deliver BRI Care Consultation. **K.J.**: Travel expenses for the Dementia Care Navigation workgroup meeting were provided by the Alzheimer's Association. **L.E.**: Travel expenses for the Dementia Care Navigation workgroup meeting were provided by the Alzheimer's Association. NIH/NIA Caregiver Outcomes of an Alzheimer's and Dementia Care Program. (Award # R21 AG054681) Role, co-investigator. Payments made to UCLA 9/1/2017 – 5/31/2020. PCORI, Pragmatic Trial of the Effectiveness and Cost-Effectiveness of Dementia Care. (Award # R01 AG061078) role co-investigator. Payments made to UCLA 9/30/2018 – 5/31/2023. NIA/NIH Comparative Effectiveness of Health System vs Community-based Dementia Care. (Award # PCS-2017C1-6534). Role, co-investigator. Payments made to UCLA 4/1/2018 – 9/30/2025. The John A. Hartford Association Dissemination of the UCLA Alzheimer's and Dementia Care Management Program. (Award # 2018-0088). Role, co-investigator. Payments made to UCLA 1/1/2019 – 12/31/2021. The John A. Hartford Foundation Expansion of the UCLA Alzheimer's and Dementia Care Management Program. (Award # 2021-0160). Role, co-investigator. Payments made to UCLA 1/1/2022 – 12/31/2024). **M.B.**: Travel expenses for the Dementia Care Navigation workgroup meeting were provided by the Alzheimer's Association. **Q.S.**: Travel expenses for the Dementia Care Navigation workgroup meeting were provided by the Alzheimer's Association. National Institute on Aging (funds to institution), BrightFocus Foundation (funds to institution), Centers for Medicare & Medicaid Services (funds to institution), Centene Corporation (funds to institution), Sibley Memorial Foundation (funds to institution). Maryland's Virginia I. Jones ADRD Council, no payments made. **S.D.**: Travel expenses for the Dementia Care Navigation workgroup meeting were provided by the Alzheimer's Association. NIH R01 AG051715, NIH R01 AGO74710. People Designs Clarity Study, $200 for Delphi panel participation.

CONSENT STATEMENT

There was no need for human subject consent.

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