SPECIAL ARTICLE

Recommendations to Improve Payment Policies for Comprehensive Dementia Care

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See related editorial by Callahan et al. in this issue.

Access to comprehensive dementia care is limited. Recent changes in billing for professional services, including new physician fee schedule codes, encourage clinicians to provide new services; however, current reimbursement does not cover costs for all needed elements of dementia care. The Payment Model for Comprehensive Dementia Care Conference convened more than 50 national experts from diverse perspectives to review promising strategies for payment reform including ways to accelerate their adoption. Recommendations for reform included payments for services to family caregivers; new research to determine success metrics; education for consumers, providers, and policymakers; and advancing a population health model approach to tier coverage based on risk and need within a health system. **J Am Geriatr Soc 68:2478-2485, 2020.**

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"Let's continue to help each other enjoy our lives, starting with our human right to medical care, living in our communities, and choosing how we want to be treated,"[1] commented Mary Radnofsky, PhD, an advocate and self-advocate for persons living with dementia.

Access to comprehensive dementia care addressing the medical, neuropsychological, and social aspects of life is limited for persons living with dementia (PLWD) and their family members and caregivers. Recent changes in billing for professional services, including new physician fee schedule codes,[2] encourage clinicians to provide new services (eg, code 99483[3] for care planning); however, current reimbursement does not cover costs for all needed elements of ongoing dementia care. Specifically, as symptoms of dementia progress, it is usually necessary to include a family member or other care partner[4-6] in clinical encounters as a strategy to support PLWD in adjusting to cognitive impairments. In this report, the term "caregiver" refers to a person providing care and support to a parent, spouse, friend, or neighbor who needs help because of a limitation in their physical, mental, or cognitive functioning.[7] Currently, systems of payment for services that enable caregiver participation in the context of medical care are underdeveloped, despite growing evidence that caregiver education and support improves the quality of care and reduces costs.[8,9]

Accelerating the use of the new professional service billing is important but insufficient.[8] New payment mechanisms are needed to promote wider use of evidence-based comprehensive care and services for PLWD. Paying for a comprehensive approach may also promote more effective and cost-effective care by raising awareness of clinicians about the availability of early interventions. Comprehensive coverage for people with dementia and their family caregivers will be an important part of an Age-Friendly Health System and follows two of the major principles, addressing mentation and what is important to older adults and their caregivers.[10,11]

With support from The John A. Hartford Foundation, Hebrew SeniorLife, and Education Development Center, a one-day conference, Payment Models for Comprehensive Dementia Care, was held in November 2019 in Washington, D.C. The conference convened more than

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50 clinicians, researchers, advocates, payers, and PLWD from across the country with expertise in models of comprehensive dementia care delivery and healthcare payments. Participants reviewed promising short-term solutions and described actionable next steps to accelerate the use of current payment models and development of new ones for comprehensive dementia care. Their expertise covered a range of payment models: Medicare fee for service, Medicare Advantage, bundled payment approaches, Medicaid, Federally Qualified Health Centers (FQHCs), and populations with difficulty accessing health care. Although not a focus of this conference, some innovative models of geriatric care, such as the Program for All-Inclusive Care for the Elderly (PACE), the Department of Veterans Affairs, and the military health system models, also address dementia and were discussed by conference participants. This report aims to summarize the conference findings and recommendations for next steps. We begin with a background section that presents a brief summary of components of dementia care in the context of a population health that recognizes the range of intensity of care needs for PLWD. Next, the section on conference outcomes presents key themes organized by each of four payment models. The final section synthesizes themes from across payment models.

BACKGROUND

Early interventions for dementia care focused on caregiver education and support, and they were usually delivered outside of healthcare settings in the context of research studies. Despite the effectiveness of numerous caregiver interventions in improving caregiver efficacy and sometimes patient outcomes, there has been limited translation of these into practice.[12] More recently, comprehensive models of care for dementia that focus on both the PLWD and caregiver were developed and tested[8,13] with promising findings on achieving the triple aim of better care, improved outcomes, and lower costs.[14] These interventions are either community based, often delivered by telephone or in PLWD's homes by staff who are employed at community-based organizations, or are health system based. Interventions of both types share many common elements (Table 1) including assessment and care planning, psychosocial interventions, and care coordination.[15] Nevertheless, models differ in staffing; scope of services; intensity and cost; efficacy, effectiveness, and return on investment; and level of supporting evidence.[16] Table 2 compares these six models currently operating in clinical or research settings in the United States:

- The Benjamin Rose Institute Care Consultation model is a telephone care coaching program employing bachelor's or master's degree social workers or nurses for PLWD and their family or friend caregivers. This model has been associated with beneficial changes in psychosocial outcomes for both patients and caregivers (eg, decreased symptoms of depression, embarrassment about memory problems, various forms of both care and caregiving strains, and social isolation).[17,18]

Table 1. Comprehensive Dementia Care Elements

Element	Description
Continuous monitoring and assessment	Continuously monitor and assess cognitive, functional, behavioral, and psychological needs as well as safety and the level of caregiver stress.
Ongoing care plan	Develop and implement a care plan that is regularly evaluated and modified as needed including advance care planning, wishes about place of residence, and attention to end-of-life care.
Psychosocial interventions	Implement interventions aimed at preventing or reducing the burden of cognitive, functional, behavioral, and psychological challenges as well as caregiver stress including care practices from innovative technology solutions.
Self-management	Provide self-management tools to enhance the skills of the person living with dementia and caregiver in managing Alzheimer's disease and related dementias, navigating the healthcare system, and engaging in activities related to person-centered goals.
Caregiver support	Identify one or more caregivers to include in evaluation, decision-making, and care planning; and provide culturally sensitive support and assistance designed to help the caregiver(s).
Medication management	Use evidence-based medication management including deprescribing medications with adverse cognitive effects; includes efforts to increase medication adherence and education about opportunities for participation in research.
Treatment of related conditions	Take steps to prevent and treat conditions related to Alzheimer's disease and related dementias, such as depression, falls, and delirium.
Coordination of care	Coordinate transitional and other healthcare services across hospitals, nursing homes, and ambulatory care and community-based settings.

Source: Adapted from Boustani et al.[15] See also Wiener et al.[6]

- The Care Ecosystem utilizes a team of non-licensed Care Team Navigators plus advanced practice nurses, social workers, and pharmacists to implement care plan protocols over the telephone and by the Internet. The term "non-licensed" is used throughout this article to refer to a category of staff whose specific titles and roles vary by program (eg, dementia care assistants, care navigators, community health workers, memory care coordinators). They are not licensed and often are filled by college or high school graduates. In a clinical trial, it was shown to improve the quality of life of PLWD and

Table 2. Comparison of Six Comprehensive Dementia Care Models

	BRI-CC	Care ecosystem	MIND	HABC	UCLA ADC	IMCC
Structure and process						
Key personnel	SW, RN, MFT	Non-licensed[a] care navigator, CNS, SW, Pharmacist	Non-licensed staff, RN, MD	Non-licensed staff, MD, SW, RN, psychologist	NP, PA, MD	APN
Key personnel base	CBO	Community	Community	Health system	Health system	Health system
Face-to-face visits	No	No	Yes	Yes	Yes	Yes
Access 24/7/365	No	No	No	Yes	Yes	Yes
Communication with PCP	Mail, fax	Fax, phone	Phone, mail, fax	EHR, phone, mail	EHR, phone	NA
Order writing	No	No	No	Yes	Yes	Yes
Medication management	No	No	No	Yes	Yes	Yes
Benefits						
High-quality care	NA	NA	NA	Yes	Yes	Yes
Patient benefit care	Yes	Yes	Yes	Yes	Yes	NS
Caregiver benefit	Yes	Yes	Yes	Yes	Yes	NS
Costs of program	++	++	+++	+++	++++	++++
Cost savings, gross	++	++	None	++	++++	++++

Source: Our analysis of data is from Bass et al.,[17,18], Possin et al.,[19] Samus et al.,[20] Callahan et al.,[21] Reuben et al.,[22,25] Jennings et al.,[23] Clevenger et al.,[26] and correspondence with C.K. Clevenger.

Abbreviations: UCLA ADC, University of California, Los Angeles, Alzheimer's and Dementia Care; APN, advanced practice nurse; BRI-CC, Benjamin Rose Institute Care Consultation; CBO, community-based organization; CNS, clinical nurse specialist; EHR, electronic health record; HABC, Healthy Aging Brain Center; IMCC, Integrated Memory Care Clinic; MD, medical doctor; MFT, marriage and family therapist; MIND, Maximizing Independence (at Home) program; NA, not available; NP, nurse practitioner; NS, nonsignificant findings but positive direction; PA, physician assistant; PCP, primary care provider; SW, social worker; RN, registered nurse; ++, least expensive; ++++, most expensive.

[a]The term "non-licensed" is used throughout this article to refer to a category of staff whose specific titles and roles vary by program (eg, dementia care assistants, care navigators, community health workers, memory care coordinators). They are not licensed, and often positions are filled by college or high school graduates.

reduced emergency department (ED) utilization and caregiver depression and burden.[19]

- The Maximizing Independence at Home program is a comprehensive home-based care coordination intervention provided by non-licensed personnel, registered nurses, and physicians. The program was shown to delay transitions from home to residential care and reduce caregiver burden.[20]
- The Eskenazi Healthy Aging Brain Center initially used a nurse practitioner dementia care manager to tailor and facilitate delivery of nonpharmacological and pharmacological care process components to individual patients in collaboration with the primary care physician. In a clinical trial, this program demonstrated effectiveness on quality measures and patient outcomes (reduced behavioral symptoms and caregiver stress by half at 12 months).[21] More recently, most of the dementia care is provided by non-licensed staff.
- The University of California, Los Angeles (UCLA) Alzheimer's and Dementia Care (ADC) Program uses a co-management model with nurse practitioner dementia care specialists working with primary care and specialty physicians.[22] In a large case series and cost comparisons with a matched control group, the program has demonstrated high quality,[23] reduced total Medicare costs, decreased nursing home placement compared with matched patients,[9] improved end-of-life care,[24] and improved patient and caregiver outcomes.[25]
- The Integrated Memory Care Clinic is an patient-centered medical home led by advance practice nurses for persons with dementia and mild cognitive impairment that provides comprehensive primary and dementia care.[26] It was shown to provide high-quality care and is associated with low ED utilization and low rates of ambulatory-sensitive hospitalizations.[27]

As the development of models for dementia care has evolved, the concept of a population-based approach has been described in which different services are deployed to tiered groups of PLWD based on the severity of dementia, complications, and recent (eg, past year) utilization of health care (Figure 1).[28] This approach is more efficient (ie, it would be wasteful to provide expensive services to PLWD who do not need this level of intensity) and considers a health system's available resources for providing comprehensive dementia care. In a population-based approach, resources are also more broadly considered including assessment of available family and community supports, access to covered healthcare services, and health equity concerns such as literacy and ability to access services based on residence location. Once the population is defined and characterized, more intensive services that are included in health systems–based dementia care could be provided to PLWD who are having dementia complications (eg, behavioral and

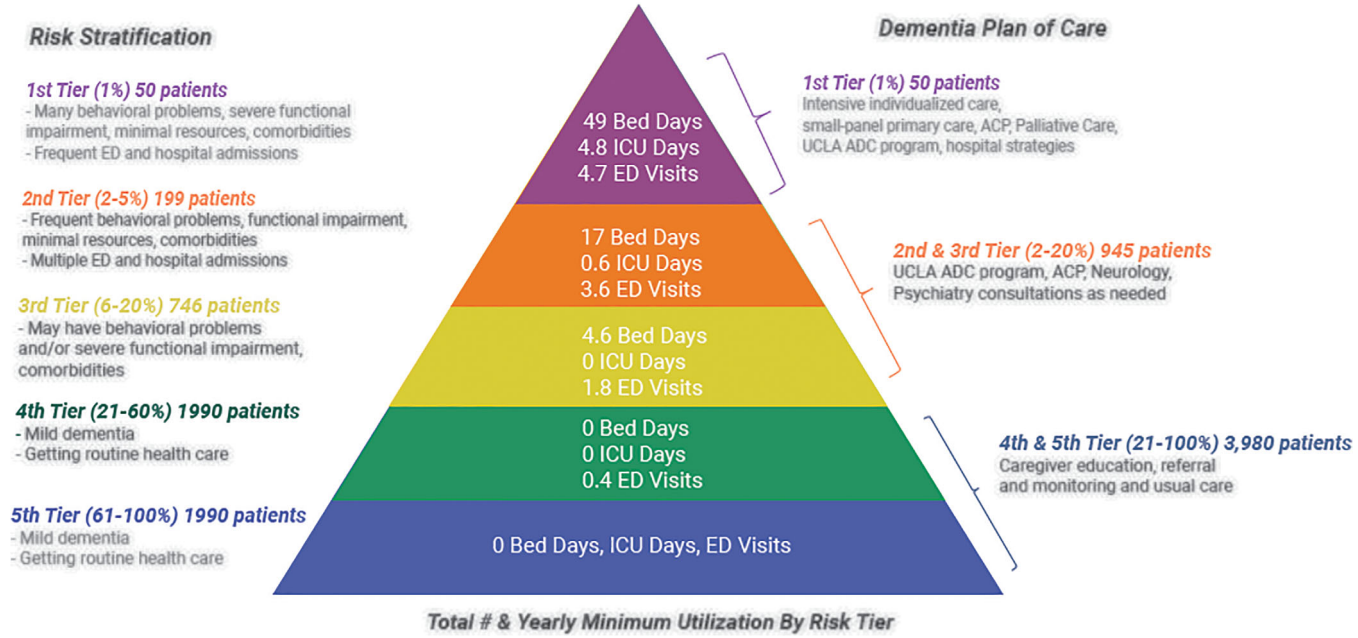

Figure 1. Population-based dementia care model shows a tiered approach to addressing subpopulations of patients. The first tier patients received the most intensive care; second and third tier patients receive moderate-intensity care from clinicians; and fourth and fifth tier patients receive education and monitoring, with the expectation that at a future date there may be a need to enter a tier with more intense services. Source: Reuben DB, Gupta R, Skootsky SA. How a population-based approach can improve dementia care. Health Affairs. https://www.healthaffairs.org/do/10.1377/hblog20190506.543619/full/. Published May 8, 2019. Accessed April 17, 2020. *Note*: Use time frame July 2017 to July 11, 2018. ACP, advance care planning; ED, emergency department; ICU, intensive care unit; UCLA ADC, University of California, Los Angeles, Alzheimer's and Dementia Care.

psychological problems) or are at high risk of incurring high healthcare costs (eg, the 20% who are in Tiers 1, 2, and 3). Most affected persons (eg, the 80% in Tiers 4 and 5) might receive services that are provided through community-based models.

Use of a tiered population-based approach, although providing more enhanced services for some, still requires that basic features be available to all. Any payment model must address dementia as a chronic condition and a serious illness with complex care needs that requires a trained workforce with skills to manage the disease across the illness course. This includes applying evidence-based nonpharmacological treatments and a person-centered approach that addresses culturally specific needs and barriers. All models must also have procedures for assuring that all elements of comprehensive care (Table 1) are available including opportunities to access respite services, address transitions into and out of acute care and institutional settings, and initiate hospice services when appropriate.

At the Payment Models for Comprehensive Dementia Care conference, experts from across the country convened to review these promising comprehensive dementia care models and their core elements and strategize ways to accelerate their adoption through payment reform.

CONFERENCE OUTCOMES

The Payment Models for Comprehensive Dementia Care conference included four breakout groups defined by payment structures: (1) fee for service, (2) Medicare Advantage, (3) bundled payment, and (4) Medicaid, FQHCs, and rural settings. Each group was tasked with identifying viable scalable aspects and limitations of the payment model for covering elements of comprehensive dementia care as well as any short- and long-term strategies for accelerating their use. Following the breakout groups, participants reconvened to report and discuss results, and to generate recommendations (Table 3).

Fee for Service

The traditional fee-for-service payment structure, in which providers code and bill for individual services, is currently insufficient for covering comprehensive dementia care. Essential elements of comprehensive care, particularly caregiver support and community-based services, are not reimbursed under this model; nor are services provided by non-licensed care providers. Although available codes cover some necessary dementia care services, provider uptake of these codes has been limited due to lack of provider awareness and barriers to meeting necessary visit components within existing outpatient primary care practice structures.[29] For example, meeting the requirements of these codes may require adjustments to clinic workflows and visit schedules, updating electronic health record systems, and modifying billing processes.

Strategies that can be used to improve coverage for services through fee for service include (1) mapping core elements of comprehensive dementia care models to existing Medicare Physician Fee Schedule (MPFS)[30-32] coding to explicitly demonstrate appropriate use, (2) educating clinicians and health systems about the MPFS coding relevant

Table 3. Summary of Findings and Recommended Strategies

Payment structure	Viable aspects of the payment structure	Limitation(s) of the payment structure	Short-term strategies for accelerating coverage	Long-term strategies for accelerating coverage
Fee for service	Fee for service currently is not a viable structure for covering all elements of comprehensive care	Some core elements of comprehensive care are not covered, particularly related to caregiving and community-based services Fees do not adequately reflect time intensity and resource use for PLWD Newer codes are underused and may not align with roles and workflow across specialties	Map core elements of care to existing codes Educate providers on which elements of care are covered including strategies for use of existing codes Determine specific services needed at each tier of population health model and match them to payment Identify gaps where there is not a mechanism for covering aspects of comprehensive care	Gather information needed for CMS to modify codes to better cover provider costs to deliver services Create new codes for uncovered services
Medicare Advantage	Medicare Advantage structure embraces chronic disease that can be leveraged to support comprehensive dementia care	Plans lack infrastructure for delivery of comprehensive dementia care Caregiver needs may not be identified or covered. Investments in better care for PLWD may impact costs over multiple years (not immediate alignment)	Increase awareness for using flexible supplemental benefits and apply new risk adjustment factors Define, teach, and incorporate core elements of comprehensive care into existing plans	Articulate how comprehensive care can translate into savings for provider systems Develop strategies to reduce concerns of adverse selection Develop clear dashboards of comparative benefits so consumers can make informed decisions
Bundled payment	Bundled payment is currently not available as a structure for covering comprehensive care	Reimbursements for episodes of care for related conditions do not cover all elements of comprehensive dementia care	Define how dementia care differs from other advanced illnesses (eg, medical and social needs, need for caregivers and proxy decision-making)	Study the population health model to determine if increasing intensity of services due to dementia complexity is associated with better care and lower cost
Medicaid, FQHCs, and rural settings	Telemedicine and other strategies for reaching remote populations can be leveraged to improve access to care	Economically disadvantaged populations face challenges to accessing care and models must be adaptive and agile High rates of provider turnover In some areas there is lower incentive to focus on older adult populations because they are a small percentage of the population served	Identify appropriate success metrics Determine specific services needed at each tier of population health model and match them to payment Identify gaps where there is not a mechanism for covering aspects of comprehensive care	Develop strategies to better assess health disparities including anticipating future demands for highest need populations, and support early access to care

Source: Our analysis of data is from the Payment Models for Comprehensive Dementia Care Conference, 2019.
Abbreviations: CMS, Centers for Medicare & Medicaid Services; FQHC, Federally Qualified Health Center; PLWD, persons living with dementia.

to elements of dementia care, (3) gathering information that the Centers for Medicare & Medicaid Services (CMS) would need to modify codes, and (4) creating new codes for uncovered services.

The ADC Program dissemination team has begun the work of mapping existing codes to core elements of the ADC Program to guide dissemination sites as they make decisions about return on investment for implementing the ADC Program.[33] This work can be leveraged and applied more broadly to other types of dementia care models. Following the work of mapping elements and codes, efforts should focus on disseminating this knowledge and

educating providers on the availability of the existing codes and how they may apply to the services they are providing. For example, CMS should highlight and provide guidance on how to use existing and recently established codes (eg, new codes for care planning and telephonic services).

Medicare Advantage

Under the Medicare Advantage structure, private insurance companies are approved by Medicare to offer bundled plans to patients for which the company receives a fixed monthly payment for all services rather than separated payments associated with specific clinical services.[34] Premiums, deductibles, copayments, items, services that are covered, and other aspects of care vary by individual plan. Similar to the fee-for-service structure, these plans typically lack coverage for core elements of comprehensive dementia care. However, the Medicare Advantage structure permits flexibility in managing chronic disease, which positions it as a stronger model to build on for comprehensive dementia care.

Immediate strategies for accelerating the effective use of Medicare Advantage to cover comprehensive dementia care include (1) defining, teaching, and incorporating core elements into plans, and (2) increasing awareness of successful models. One such model is the application of flexible supplementary benefits that were expanded in 2019 to support daily maintenance of health and in 2020 to cover access to services that had not typically been considered health related but have a "reasonable expectation of improving or maintaining the health or overall function [of chronically ill] enrollees."[35] A second example is new risk adjustment weighting factors that can be applied to dementia care to reflect complexity more accurately and cover the costs of appropriate care for dementia patients.

Three longer term strategies for accelerating the use of the Medicare Advantage structure for covering comprehensive dementia care were identified. First, improving assessment and diagnosis strategies to identify and characterize the dementia population that the plans are accountable for and leveraging the resulting opportunity for cost savings by providing support for comprehensive dementia care (eg, from an economies-of-scale perspective, bigger plans with more dementia patients may be more sustainable). Second, developing strategies to address concerns over adverse selection including assessment of the factors affecting when and why patients switch between Medicare Advantage plans and traditional Medicare.[36,37] Finally, developing clear dashboards of comparative benefits for consumers so they are able to choose plans based on their dementia-specific needs.

Bundled Payment

Bundled payment arose as an alternative model developed to aid a shift to value-based care. Under this structure, provider systems receive a total budget for services addressing a defined episode of care. Depending on the actual cost of care provided to patients, providers may share in savings or, if actual costs exceed the set budget, may incur losses.[38] In its current form, like fee for service and Medicare Advantage, bundled payment is not a viable option for supporting comprehensive dementia care. A main concern is that reimbursements for episodes of care do not adequately cover dementia as a chronic condition; nor do they cover costs related to caregiving such as education and training to develop caregiver skills or support of respite care to reduce caregiver burden. The bundled payment workgroup concluded that one path forward under this structure is advocacy to encourage CMS to implement a bundled payment for dementia. These steps include (1) defining how dementia care is different from other advanced illnesses, (2) designing a payment structure according to the population health model (eg, understanding appropriate cutpoints for tiers of severity, determining the appropriate capitated payment, the feasibility of using a dynamic risk adjustment model with the ability to adapt for different geographic settings), (3) determining economic models to estimate the budgetary effect of covering care through bundled payment including the extent to which dementia severity and associated care increases or decreases spending on other high-cost conditions (eg, heart failure, cancer), and (4) implementing bundled payment models, evaluating value, and then extending the reach to large populations. Other types of carveouts could also be considered, such as widespread expansion of PACE[39] or adjustment of criteria for PLWD to qualify for hospice enrollment.[40]

Medicaid, Federally Qualified Health Centers, and Rural Settings

The fourth payment structure as defined for the purposes of the conference brings together models of payment including Medicaid, FQHCs, and rural settings that are designed to reach underserved populations. Medicaid is a benefit offered jointly by federal and state governments to provide free or low-cost care to eligible people. Eligibility criteria vary by state and typically depend on income level, family size, and disability status.[41] FQHCs are community-based centers that, by meeting strict criteria, receive Health Resources and Services Administration funding to provide primary care services to underserved populations on a sliding scale. Participants were asked to also consider models focusing on the specific needs of patients living in rural or underserved areas. The populations of patients considered in this group can be broadly classified as economically disadvantaged with specific concerns centering around access to care and quality of services provided. Covering comprehensive care for rural and other underserved populations might include testing a tiered model that includes both home- and community-based services, social services, and enhanced services for patients who are transitioning between tiers of severity. Additionally, strategies must be used to speed and increase the use of telemedicine, tele-mentoring, and other innovations to reach patients in remote settings more effectively and address healthcare and community-based workforce deficits.

DISCUSSION AND CONCLUSION

In addition to short- and long-term strategies for accelerating the use of specific payment structures, a number of common themes emerged across payment structures including the need to cover services for caregivers, the need for

research and education about dementia payment models, and the promise of a population health approach.

The first common theme is recognition that providing services for caregivers is a critical aspect of comprehensive dementia care. As evidenced in Table 1, caregiving underlies multiple core elements of comprehensive care (eg, self-management, psychosocial interventions, and continuous monitoring and assessment), and engaging with caregivers to address patients' needs effectively requires time and expertise from clinical team members. At present, these services are not reimbursed under any of the payment structures. Failure to prepare caregivers for their roles and support them in these roles will result in inadequate care and potentially premature transitions of PLWD to more expensive tiers of care. The CMS Primary Cares Initiatives is one model demonstrating the importance of engaging caregivers as part of a comprehensive approach to care improvement.[42]

A second recurring theme across payment groups is the need for research and education. Across payments groups, research is needed to (1) identify appropriate success metrics regarding implementation of comprehensive care models including measurement of health outcomes and costs, (2) determine the specific services needed at each tier of the population health model and match them to mechanisms for coverage, (3) identify gaps where there is not currently a mechanism for reimbursing components of comprehensive care, and (4) develop strategies for early access to lower cost care to reduce future need for intensive services. Research must be paired with education for consumers, providers, and policymakers. Educating consumers (PLWD and their caregivers) about what comprehensive dementia care can provide will help them access appropriate services and, where these are lacking, advocate for change. Education for providers will help them use existing and new mechanisms for supporting the care they provide. Finally, education for policymakers about current gaps and opportunities in payment is necessary for them to implement relevant model changes.

Finally, the population health model approach was considered across payment groups as a promising strategy to facilitate coverage of a large number of PLWD within a health system. There is potential for the population health framework to address comprehensive dementia care while individualizing priorities and containing costs. To facilitate use of a population health approach such as that shown in Figure 1, there must be improvements in widespread early detection, diagnosis, and assessment of PLWD while they are still in a lower tier and potentially prevent or delay the need for higher level services. Barriers to early detection are well documented including workforce shortages[43] and low confidence for the yield on routine screening based on age or other risk factors.[44] Payment reform is one approach to addressing both of these barriers.

In conclusion, the Payment for Comprehensive Dementia Care conference convened experts in dementia care innovation, delivery, and payment to review promising solutions and describe actionable next steps to accelerate the use of current and new payment models for comprehensive dementia care. The results of this conference identified the core elements of comprehensive dementia care, highlighted specific opportunities and challenges to covering these elements under current payment structures, and outlined next steps for promoting improvements to accelerate coverage under these and new payment models. It will take the commitment of many stakeholders to implement accessible comprehensive dementia care across payment systems and build a truly Age-Friendly Health System that integrates family members into treatments and fully engages PLWD, the most vulnerable older adults.

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