HHS Public Access

Author manuscript

Alzheimers Dement. Author manuscript; available in PMC 2019 January 01.

Published in final edited form as:

Alzheimers Dement. 2018 January ; 14(1): 104–114. doi:10.1016/j.jalz.2017.10.006.

Home is where the future is: The *BrightFocus Foundation* consensus panel on dementia care

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Abstract

Introduction—A national consensus panel was convened to develop recommendations on future directions for home-based dementia care (HBDC).

Methods—The panel summarized advantages and challenges of shifting to HBDC as the nexus of care, and developed consensus-based recommendations.

Results—The panel developed five core recommendations: (1) HBDC should be considered the nexus of new dementia models, from diagnosis to end of life in dementia; (2) new payment models are needed to support HBDC and reward integration of care; (3) a diverse new workforce that spans the care continuum should be prepared urgently; (4) new technologies to promote communication, monitoring/safety, and symptoms management must be tested, integrated and deployed; and (5) targeted dissemination efforts for HBDC must be employed.

Discussion—HBDC represents a promising paradigm shift to improve care for those living with dementia and their family caregivers: these recommendations provide a framework to chart a course forward for HBDC.

Keywords

Alzheimer's and related dementias (ADRD); Dementia; Home-based care; Community-based care; Workforce; Technology; Cost effectiveness; Payment models; Care financing

Purpose and Description of Consensus Panel

This report presents findings and recommendations of a national consensus panel (Panel) convened by the Johns Hopkins Translational Aging Services Core in the Department of Psychiatry and Behavioral Sciences with support from the *BrightFocus Foundation*. The purpose of the Panel was to draw attention to the overwhelming service burden that dementia and family caregiving will pose in the future, to focus on home-based dementia care (HBDC) as a critical component of care services for people with Alzheimer's disease and related dementias (AD) in the coming decades, and to impact the field by disseminating concrete recommendations for future directions in HBDC. Specifically, the Panel reviewed key issues, barriers, and opportunities relating to payment and care financing; evidence based research, dissemination, workforce, and technology.

The multidisciplinary expert panel consists of 15 nationally recognized clinicians, researchers, health economists, advocates, policy makers and health services administrators from diverse organizations (e.g. Johns Hopkins University Schools of Medicine, Nursing, Public Health, Hopkins; Indiana University; University of Pennsylvania; University of Michigan; Veterans Administration; Maryland Department of Health & Human Services; Centers for Medicare and Medicaid Services; LECMA, AFi, and iSAO France) and disciplines (e.g., psychology, sociology, economics, health care administration, neuroscience, geriatrics, psychiatry, gerontology, nursing).

The Panel regularly met by teleconference (4 meetings), supplemented by email communications, over an 18-month period, and convened for one in-person full day meeting (December 2015). The full day meeting, which was recorded and dictated by a professional science writer, included a series of 6 presentations by Panel Members, each followed by full group discussion to develop recommendations. Recommendations were further refined through subsequent teleconferences and email communications. While the Panel implemented a semi-structured format for identification of important topic areas, facilitation of discussions on each topic, and agreement on recommendations by the Consensus members, the Panel did not employ formal consensus classification techniques like the Delphi Method. Preliminary and abbreviated Panel findings have been presented previously at the Alzheimer's Association International Conference (AAIC), the Patient Centered Outcomes Research Institute (PCORI) pre-Research summit meeting, and the 2017 National Research Summit on Care, Services and Supports for Persons with Dementia and Their Caregivers which will inform the U.S.

In this article, we discuss dementia care across the long term care services continuum, define home-based dementia care (HBDC), provide a rationale shifting the dementia care paradigm to the home, discuss the relative advantages and challenges of a home-based approach, and put forth a set of key consensus-based recommendations for moving forward with a robust and evidence-based approach to HBDC in an era of health care reform.

Toward Optimal Dementia Care Across the Continuum

There is a critical and urgent need to provide higher quality and lower cost services to persons with dementia. There are an estimated 46.8M persons living with dementia worldwide, and this number will nearly double every 20 years to a projected 131.5M in 2050. Dementia prevalence estimates for persons aged 60 and older range between 4.6% (Central Europe) to 8.7% (North Africa and the Middle East), with most regional rates falling between 5.6 and 7.6%. Projections suggest that low to middle income countries will experience disproportionately high increases prevalence rates, increasing from accounting for 58% of all global dementia cases in 2015, to 68% in 2050.[1]

In the US, of the estimated 5.4 million Americans living with dementia, unpaid family caregivers typically provide the lion's share of dementia care, with millions of American family members providing care to home dwelling family members or friends with dementia.[2,3] Over the trajectory of the illness, it is common for persons with dementia to have health care encounters and receive services in a variety of settings including outpatient clinics,

inpatient hospitals, rehabilitation units, behavioral health-focused medical units, nursing facilities, assisted living, and hospice facilities. In fact, among users of long term services in the U.S., national estimates suggest the prevalence of diagnosed dementia is 50% in nursing homes residents, 45% among hospice patients, and 31% among home health agency patients.[4] For assisted living national estimates suggest that about 70%, or 7 out of 10 residents, have some form of cognitive impairment.[5] International studies of the prevalence of dementia in long-term care homes show similar trends.[6] Importantly however, at any given time, most living with dementia are cared for at home. About two-thirds of the 5.4 million Americans with dementia, are not in acute, post-acute, or long term residential settings, but are instead living in their own homes in the community. The proportion cared for at home is even greater, about 94%, in low and middle income countries that have very fewer care and support resources.[1]

Care for persons with dementia is complex due to a relative lack of condition-specific continuity and coordination across care settings, inadequate care in the outpatient arena, limitations in provider education, time and resources, and lack of financial alignment and incentives. Thus in the context of the considerable health system fragmentation and poor coordination within and between health care and community-based support systems, dementia care is rarely delivered as a comprehensive set of services.[7] These factors can lead to potentially preventable emergency department visits, inpatient hospitalizations, and premature institutionalizations.[8,9] Often even receipt of a timely diagnosis, which is absent about half of the time[10], presents a major barrier to entering or accessing dementia-focused care and support services. Further, social and supportive services, critical to meeting dementia-related care needs, are fragmented and often not reimbursed through health insurance.[11] As a consequence, many persons with dementia and their family caregivers have needs that go unmet.[12–14] Common unmet needs of persons with dementia include timely recognition and evaluation, general medical care, safety (e.g., home safety, driving), ADL support, activities, behavioral management, and environmental needs.[13–20] Caregivers, who are critical factors in the equation, often lack emotional support, respite time, disease education, and care for their own mental health and medical, and key services to meet these needs are often underutilized, not locally available, too expensive, or not accessible.[13,14,21] These unmet needs, particularly caregiver burden, falls and acute medical problems, behavioral symptoms exacerbate poor outcomes and increase risk for costly institutionalization.[22–24]

Although curative dementia treatment development is ongoing, the reality is that it will be some time before effective disease modifying treatments are available. Comprehensive and effective dementia management interventions must be widely implemented to care for those affected now and in the foreseeable future. Optimal “dementia care across the continuum” involves putting in place proven, person- and family-centered interdisciplinary interventions to maximize quality of life and minimize complications; maintaining this support and guidance through the course of the illness as the needs of both the person with dementia and the caregiver change; and, successfully connecting medical, social, and supportive care professionals, workers, and informal caregivers over the course of the illness to achieve patient centered outcomes in the care delivery and transitions between care settings. Because of the unique needs or vulnerabilities of the person with dementia and caregivers, and

heightened use of a variety of care services and settings, it is particularly important to focus on communication, coordination, and connection between providers, informal caregivers, and others involved in care.

Proactive coordinated dementia care and caregiver support, including high-quality primary care, is associated with fewer health care encounters and transitions (emergency department visits, hospitalizations),[9] can improve quality of life and function in dementia[25–27], delay placement in long term care, and improve caregiver outcomes[28,29] and is supported by practice recommendations.[30] The best outcomes are associated with comprehensive person- and family-centered services that are timely, responsive, flexible and tailored to individual need. These principles of quality care align with the goals of global action plans to address the challenges that dementia poses worldwide.[31]

Home is Where the Future Is

> "Home-based dementia care should be considered the nexus of new long term care models."

We posit that the home, rather than outpatient, inpatient or long-term care settings, is the most important care setting, and should serve as the nexus of dementia care as we move forward with dementia health policy planning and health care reform to improve care and efficiency. From a public health perspective, optimizing dementia care in the home to reduce or delay transitions to other care settings may provide the maximum population-level benefit, and is desirable given the overwhelming preference of older people to remain in their homes and familiar communities for as long as possible,[32] the huge economic costs associated with acute health care use and premature long term institutionalization,[33,34] as well as evidence to suggest it is associated with higher quality of life compared with nursing homes.[35] Home-based dementia care (HBDC) can be defined as care and support provided to a person with dementia in his/her own home by informal caregivers (family, friends, neighbors, fictive kin) and formal caregivers (health professionals, community workers), using a range of assistive technologies to meet medical, psychosocial, functional, behavioral, spiritual, material, safety, and environmental needs. Basic principles guiding comprehensive HBDC are listed in Table 1.

A number of converging societal trends support the emphasis on the home as the nexus for dementia care: (1) the current and projected prevalence of disease with uncertainty about the emergence of "curative" treatments for dementia in the near future; (2) anticipation emergent treatments may prolong the duration of dementia, thus increasing its point-prevalence as well as longer period of time needing care, (3) the desire of older persons with dementia and their families to remain at home, (4) the recognition that persons with dementia have social, environmental, emotional, safety and support care needs that go beyond medical care and services, (5) the need to reduce health care costs [10] and improve quality of care by shifting care from traditional, institutional long term care to home and community based options,[36] (6) the mismatch between institutional long term care supply and need for long term care services, and (7) the shrinking pool of family caregivers available to provide care and the potential numbers of people who will require care.

Focusing on the home as the nexus of dementia care has several advantages. From a conceptual standpoint, providing HBDC underscores the importance of a holistic, integrated approach to dementia care, and enables a wider range of needs for the person with dementia and his/her caregiver to be identified and addressed including needs at a contextual and environmental level. This focus also includes the opportunity to assess and intervene on needs such as fall- and wander-risk management, challenging behaviors, medication administration and adherence, nutrition and hydration, and other home safety issues that may not be easily uncovered during a typical office-based outpatient primary care visit but which drive higher health care utilization and lower quality of life. Further, HBDC provides a framework for implementing a wider range of care strategies, interventions and technologies, by providing improved wrap-around care for the person with dementia and the family using the home setting as a natural conduit.

There is a growing evidence-base on discrete and multicomponent interventions being developed for dementia care in the home setting—some of which are quite promising. These may focus solely on the person with dementia, the caregiver(s), the dyad, the environment, or multiple areas, and can be delivered by a range of health care professionals or other skilled community workers. Interventions are diverse and include caregiver coping interventions or education; behavioral intervention such as customized activities, assistive technologies and devices; web-based decision support tools; and care management or care coordination.[37] Interventions are delivered with in-home visits, telephone visits, virtual support groups, remote device monitoring, or combinations, sometimes paired with provider office visits. Collectively, these are being tested on a range of outcomes including mood, behavior, physical health, quality of life, nursing home placement, medication adherence, socialization, satisfaction with care, cost effectiveness, use of health services, caregiver burden, or caregiver mastery and coping. There is an emerging market for home-based “dementia-” or “Alzheimer's care,” especially among managed care companies involved in long term services and supports,[2] home health care or geriatric case management, as well as for technologies or devices for homes including those focused on safety and health monitoring. The quality and effectiveness of these products has not been clearly demonstrated.

HBDC offers an opportunity to bridge the continuum of long term care services and supports (e.g., medical, personal and social care) with other types of community supports (e.g., faith based organizations) and informal social supports (e.g. neighbors, friends, community members). Providers of care may include different professional providers, skilled community workers, or informal care contributors. Professional providers frequently involved in HBDC are social workers, home health nurses, home health aides, physical therapists, occupational therapists, and sometimes physicians, geriatric psychiatrists, podiatrists, or dentists who make house calls or provide services through telehealth.

Finally, focusing on HBDC provides a significant opportunity for cost and resource savings by reducing or delaying nursing home expenditures[38] and reducing acute care costs through interventions such as home safety efforts (e.g., decluttering a home to reduce fall risk, thereby avoiding hip fracture) that may reduce emergency department visits or inpatient stays.

In the sections below, we provide the Panel's summarization of key topic areas, opportunities and challenges of HBDC care: payment and care financing, workforce development, technology advances, and dissemination to stakeholders (e.g. patients, family caregivers, payers, providers, insurers).

Paying for Dementia Care at Home

> "New payment models are needed to stimulate, reward, and support home care practices."

Dementia causes a significant and increasing financial burden on families and societies and costs will grow exponentially over time. Worldwide costs for dementia totaled $818 billion in 2015 US dollars, and is expected to top 1 trillion (US dollars) by 2018. Forecasting models that account for increases in prevalence and increases in per capita costs, suggest around a 6.5% per annum increase in total costs of care. [39] As one of the most expensive chronic conditions in the U.S.,[33] total costs for all Americans with dementia was estimated at 259 billion in 2016, with $131 billion (51%) paid by Medicare, $44 billion (17%) by Medicaid, $56 billion (22%) out of pocket, and $28 billion (11%) from other sources; projections suggest annual spending will rise to $1.1 trillion by 2050.[10] Average annual cost for Medicare beneficiaries with dementia are 3 times as higher ($23, 497) compared to those without ($7,223), and an estimated 23 times higher for older Medicaid beneficiaries with dementia ($8,182) compared to those without ($349).[34] There is substantial variation, however, in costs of caring for persons with dementia, and costs differ by care setting.[38,40] Cost of illness studies show that the average annual cost per patient totals $30,554 and up to over $70,000 involving mixed care setting, with nursing home care as a main cost driver. [38,41]. Informal family members often provide financial support and unpaid time. An estimated 18.2 billion hours of unpaid care was provided in 2016, valued at $230.1 billion in wages. [3]

Cost financing for dementia is a considerable challenge. HBDC is rarely covered by Medicare and private insurers, and while Medicaid for low-income individuals funds some HBDC care, it reaches only a small percentage of those in need. Under the Community First Choice program established by the Affordable Care Act, for example, only eight states cover home-based care for Medicaid beneficiaries who would otherwise require nursing home care.[42] Most of the other state Medicaid programs cover home- and community-based services (HCBS) for low-income individuals with disabilities who would otherwise qualify for nursing home care under waivers, but these too reach only a portion of those in need because of waiting lists or restrictions on eligibility.[42] Innovative translation projects targeting home-dwelling Medicaid recipients with dementia are currently underway[43], which will hopefully support wider dissemination. Further, only one-fourth of Medicare beneficiaries with physical and/or cognitive impairment are covered by Medicaid.[44] In limited situations, Medicare covers physician visits in a home setting or home health services by nurses following hospitalization and physical therapy services. However, most health and social care professionals trained in the care and support of persons with dementia and their family caregivers are not covered by Medicare.

The absence of insurance coverage for HBDC under Medicare is the *single largest obstacle* to the diffusion of innovative models of care for persons with dementia. In recent years, the Center for Medicare and Medicaid Services has funded testing such innovative models as Independence at Home, which pays for primary care physician services in the home, Hospital at Home, which provides services equivalent to inpatient hospital settings in the home for patients with select conditions, and models of care such as the Maximizing Independence at Home (MIND at Home) for persons with dementia.[45–48]

Early evidence from these innovations suggest the potential for improvements in patient outcomes, functioning, and quality of life at a potentially lower cost, including reduced hospitalization and delayed or avoided long-stay nursing home institutionalization. There are some data from the Medicare Demonstration Project to suggest that it may be possible among certain beneficiary groups to spend more on home-based care than the cost of nursing home care [49]—further cost analyses are warranted to understand the potential for cost savings over the course of dementia. Earlier diagnosis of dementia by primary care practices could also yield important savings.[50] However, in general, there are few data examining the impact of these programs on cost saving specifically *among persons with dementia*.

Importantly, savings associated with the delivery of innovative models of care do not accrue to the organizations that incur the cost of providing the services. To realize a return, organizations providing such services need to contract with managed care plans such as Medicare Advantage Special Needs Plans or Medicaid managed care plans – but such organizations cover only a minority of those in need of HBDC and may be skeptical of savings, or anticipate reaping the savings without paying for the services. Further, they are unlikely to provide upfront assistance with capital costs or the costs of training qualified personnel.

Spreading innovative models of HBDC will require *fundamental change in covered CMS benefits*. A key determinant of success will be designing payment models that show promise of achieving better outcomes and lower acute and long-term care costs. Payment approaches that stimulate collaboration and integration of care across acute, residential, and long-term services and supports through shared savings need further policy development. This blending could be the evolution of Accountable Care Organizations into Integrated Care Organizations that take financial risk for long-term care costs as well as Medicare services, or could involve more modest steps such as Medicaid and/or Medicare payment of care management fees for services in the home and shared long-term care savings.

A recent policy proposal suggests one pragmatic way to begin to improve coverage for HBDC. Medicare Help at Home is a policy proposal to add a supplemental home and community based services coverage option for Medicare beneficiaries.[44] A benefit of up to $400 per week ($20,800 per year) is designed to cover up to 20 hours a week of personal care or equivalent cash benefit for other home and community-based care. Individuals enrolled in Medicare Help at Home would qualify for this benefit once they have developed serious physical and/or cognitive impairment. Beneficiaries who receive services all contribute toward their cost, ranging from 5 percent of cost for those with incomes below 150% of the federal poverty level (FPL) to 15% for those between 150-199% of FPL, 25%

for those between 200-400% of FPL, and 50% for those above four times the poverty level. Based on the eligible population and assumptions about participation and utilization rates, it is estimated that the Medicare Help at Home benefit could be financed by monthly premiums of $33 paid by all Medicare beneficiaries, and an incremental payroll tax on employers and employees of 0.3% each. The Medicare Help at Home proposal also contains provisions to improve care coordination and quality for beneficiaries. It gives beneficiaries the option of obtaining care from Integrated Care Organizations (ICOs) – an extension of the current Accountable Care Organizations. These organizations would be responsible for care coordination, support of family caregivers, and ensuring that an overall plan of care is developed and implemented based on patient and family preferences. ICOs would report on quality of care and how well they are able to meet patient and family preferences for care and continuing to live independently. They would have an incentive to adopt promising models of delivering services that reduce hospitalization and avoid or delay long-stay nursing home placement such as by providing physician and hospital services in the home and innovative models of care coordination.

The proposal would benefit Medicare beneficiaries who face the challenge of serious physical or cognitive functioning. It could improve access to home and community long term services and supports, reduce the financial burden of out-of-pocket costs, assist family caregivers in providing support to maintain independent living longer, reduce health risks and prevent avoidable hospitalization and emergency room use. Most of these benefits would be realized by the beneficiaries receiving services. However, if well designed, the benefit could also result in at least partially offsetting-savings from reduced entry into Medicaid.

While we argue that HBDC will lead to cost savings overall, the care can require significant upfront outlay to implement effectively. Further, any shifts in the care paradigm to HBDC will need to be accompanied by explicit consideration of the informal caregiver so as not to place further financial and time burdens on already strained informal caregivers.

Creating a Skilled Dementia Care Workforce

> “A skilled new workforce spanning long term care needs to be developed and equipped.”

Another component needed to support HBDC in the future is the critical need for a well-trained and accessible workforce. To cope with the overwhelming, rising demand for dementia care, the healthcare system needs to move away from relying on the traditional physician-oriented approaches to health care, and increasingly turn to home-based care options offered by non-medical professionals. Several societal trends will amplify the need for more home-based care in the future, including the trend that individuals are living longer with multiple chronic conditions in a smaller family size,[51] which is causing an increase in burden on what is sometimes referred to as the “sandwich” generation taking care of both their dependent children and parents. As a result, workforce issues need to be addressed in a swift, timely and flexible manner. This section will highlight some of the major workforce issues and offer potential solutions for consideration by governments, medical and

educational institutions, researchers, physicians, geriatricians, nurses, nurse practitioners, social workers, paraprofessionals, informal caregivers, and affected families.

Outpatient primary care serves as a hub of dementia care for most persons affected by the dementias in the US. While persons with dementia and their caregivers look primarily to their physicians and health care providers for support and guidance, in addition to diagnosis and treatment, few are actually equipped to provide such support. In fact, many care challenges are beyond the scope of most physicians both in terms of training as well as time and resources.[52] Thus, many caregivers find themselves navigating a loose network of dementia care supports that only increases the complexity of their role.[13] Further, because health care encounters are usually office-based, important care needs such as home safety and medication administration issues may not be readily assessed or observed. Improved care quality and well-prepared primary care providers will likely come from increased focus on primary care dementia education and coordination, as well as connection to and support from complementary community-based service providers who can share their expertise in addressing person with dementia and caregiver non-medical care needs. For example, models of dementia care management in primary care for community-dwelling persons with dementia are being developed and tested in the US and elsewhere, such as the UK, Netherlands and Germany.[53] These collaborative care models are characterized by interprofessional teams and multicomponent interventions involving the persons with dementia and their caregivers.

There is a shortage in the US, and globally, of health professionals to prepare for the growing healthcare demands of the aging population.[54] It is estimated by the WHO and World Bank that 40 million new health and social care jobs will be needed globally by 2030 (WHO, 2016). This shortage has contributed to severe access problems and quality of care for consumers, excessive provider costs due to continual recruitment and retraining, and extreme workloads and high injury rates for care providers.[55] A number of short-term and long-term issues have contributed to the current instability of the workforce that has hindered the ability to provide services in both facility-based and home-based care, including: low wages and lack of benefits, lack of healthcare for many workers; poor working conditions with inadequate training and supervision that contributes to a high injury rate[55]; a high turnover in personnel that contributes to both a constant shortage of workers with training, and to a high cost for providers as they constantly recruit replacements[56]; lack of adequate certification and specialized eldercare education programs and teachers[57]; lack of a workforce skills to adapt to new challenges in caring for an increasingly diverse and aging population with complex comorbidities[58–60]; and a disruption to affordable, safe, and personalized care for affected families. One of the common themes in global and national actions plans for addressing the dementia crisis is the need for an adequately trained workforce in all aspects of dementia care.[31,61,62,1] The availability of a skilled workforce is foundational to achieving other key objectives of these plans.

In achieving solutions, a balance must be struck between affordability of safe, high-quality care for families, and the pressing need to recruit, train, and retain the best workers to support the changing definition of what it means to be aging at home. There is a slowly simmering workforce crisis that will become increasingly dire as more of the baby boomer

population becomes older than 65 years. The Panel identified several key areas of focus that begin to address the home-based care workforce crisis including elevating worker status and compensation, improving training and work conditions, and providing incentives and reimbursement changes to reward employers for creating a well-trained, skilled, and diverse workforce (Table 2).

Opportunities for Technology to Support Home Based Dementia Care

> "New technologies to promote best practices must be tested, integrated and deployed."

Technology can also play an important role in facilitating the success of patient centered interventions, particularly in the home setting. While somewhat overlapping, dementia technologies can be divided into five general categories: 1) diagnostic/assessment; 2) monitoring; 3) assistive; 4) therapeutic and 5) caregiver supportive.[63,64] For example, in the home care setting, assessment technologies could be used to tailor individualized interventions and to provide specifics about the dose and timing of interventions delivered to individual participants. The latter knowledge can be used for program evaluation, as well as to learn what interventions are most successful for specific individuals. As another example, caregiver supportive technologies can provide web-based integrated inventories of resources available to persons with dementia and caregivers residing in homes. Such web-based links can help patients, families, and other caregivers access specific resources, for example by setting up appointments, purchasing equipment, or communicating with the outside world.

Other forms of caregiver supportive technologies can also be used to identify, train, and monitor the formal and informal workforce that will deliver HBDC in the future. Novel multimedia training programs are being developed such as the WeCareAdvisor™ which is a web-based tool for caregivers of individuals living with dementia to assist them in the assessment and management of challenging behaviors. [65] With such caregiver training technologies, ongoing certifications can be administered, and quality control can be overseen. At the same time, technology can be used to access the workforce or potential workforce through marketing and other efforts.

Monitoring technologies such as wander management systems (e.g. bracelets or devices that alert if a boundary or threshold has been crossed) have been in use in residential care like assisted living settings for some time to improve safety and reduce elopement. Newer monitoring technologies are becoming available that can facilitate real time interactions with persons with dementia and caregivers wherever they might be. This monitoring will consist of devices with specific characteristics, for examine monitoring vital signs, movement, ambulation, etc. It will allow direct communication between care management teams, clinicians, and others with persons with dementia and caregivers in the home. Real time monitoring lays the foundation for real-time responses to crises or aberrant readings. The big challenge of this application of technology of course relates to confidentiality and privacy which will have to be closely guarded.

Finally, assistive technologies compensate for an individual's reduced abilities and will be clearly useful in keeping persons with dementia in the home setting. Examples include

medication dispensers with timers and alarms to assist with adherence and reduce medication errors, or technologies focusing on therapeutic aspects of care such as fostering engagement and activity (e.g. provide activities including videos, pictures and games tailored to the person with dementia).

Despite the potential for such technologies and an ever increasing number of products and devices coming onto the markets each day, very little evaluative data are available on the safety, use, effectiveness, costs, and unintended consequences of such available technology for HBDC, representing a substantial knowledge gap.[66] Further, it is questionable how well current product development is informed by persons with dementia and their caregivers and the daily life experiences, or perceived useful these products in dementia care at home.[67] These are important gaps in knowledge that should be addressed to better understand the potential impact of technology in supporting HBDC.

Translational Challenges for Disseminating Home-Based Dementia Care

> "More effective development of value, understanding of competing local priorities and adaption, and improved communication about home-based care are needed."

Home-based models of care represent an important departure from the current organization of health care services paradigm for older adults with dementia and we have already highlighted a number of opportunities and challenges to this shift including financing, workforce issues and technology. There are several addition key challenges in moving home-based models of care from the narrow realm of research to the widespread and diverse communities across the nation.

First there is the perceived value of dementia interventions. Researchers develop and test best practice models of dementia care in research studies, which are typically characterized by small groups of highly selected and homogenous groups of patients receiving interventions in well controlled settings.[68–70] Translation to the "messiness" of real world practice settings often dilutes impact and policy makers and payers often view results from these controlled settings as a best case scenario. Thus, the true value, in the eyes of payers and policy makers, may be questionable. Also, policymakers and payers often have unique needs and goals, and attach different values to the costs and benefits of an intervention than researchers, patients, or families. When the value of a new model of care remains controversial or debatable in the eyes of health system decision-makers (or insurance benefits administrators), diffusion remains limited. For example, many payers have not, or are just beginning to develop a clear understanding of the significant impact of dementia on resource use and service intensity among their patient populations—so they may not yet be able to fully appreciate the potential return on investment for adoption of dementia interventions. Further, to the extent that value is defined as cost savings, new models of care that offer additional medical and non-medical services, which are needed for dementia care, to already underserved populations will be disadvantaged. Likewise, to the extent that value is defined by decreased mortality, decreased functional impairment, or cure, new models of care focusing on progressive illnesses like dementia will be disadvantaged. Finally, the perception of demand for new dementia care models from the consumer base is still low.

Dementia is a highly stigmatized condition, with a misperception that “nothing can be done.” The needs and care requirements for persons with dementia and their family caregivers too often remain hidden to the system until a serious crisis emerges. For this reason, early efforts at improving implementation and dissemination may include activation of market demand through the activation of advocacy groups and patient families and more effective communication about the need, benefits, and value of HBDC to the public and other stakeholders.[71]

Competing priorities for policy-makers and payers is another challenge to diffusion of new models of care. Given that populations of older adults suffer from multi-morbidity and thus present competing priorities for care, interventions that offer the most benefit to the many may outweigh other options. New models of home-based care may also compete for space and resources within geographic areas, availability of skilled care providers, within the structure of health systems for resources for programming or staffing (e.g. ACOs), or for support within the technical infrastructure of a health system (e.g. electronic health records).

Adaption of interventions to specific contexts represents another barrier.[72–74] Organizations usually cannot simply take an intervention “off-the-shelf” and directly apply it to their local settings. Intense staff training or certification requirements, lengthy assessments, setting, differences in staffing types and environmental resources, patient population case-mix differences, financing, and regional, local and organizational culture all present complexities that may make translation impractical or even impossible in some settings. Further, attempts to adapt intervention to local contexts may risk changing the intervention so much so that it no longer represents the original evidence-based model, possibly rendering the intervention ineffective. At an individual-level, adaptation and tailoring of interventions to persons with dementia and their caregivers (the dyad) are unique and a key feature of HBDC. Models of care may need to adapt to cultural, ethnic, or racial diversity, low health literacy, low income, or family dynamics within the setting of an individual home. At the federal level, models may need to adapt to changing regulations, changing quality criteria, and changing payment models. Implementation teams sometimes adapt by embedding the intervention within a local priority that is already moving forward, coupling their intervention with common comorbid conditions, or engaging local champions to enable and encourage the change in practice

Summary

HBDC represents a promising person-centered and potentially cost efficient paradigm shift. Given uncertainties about “curative” treatment for Alzheimer's and related dementias, and the likelihood that the number of persons living with dementia requiring care will exceed current projections, there is a national imperative to improve the ability to look after per living with dementia and support their caregivers in community-based homes for as long as possible, with dignity and good life quality. Evidence supports the premise that HBDC can be structured in ways that are systematic and that can produce quality clinical outcomes. Early research suggests that HBDC is also cost-effective and could potentially be supported through cost offsets seen by reducing utilization of higher levels of care such as nursing homes, emergency departments, and acute hospitals. The cost offset potential across settings

and types of care are particularly promising in an era of ACOs and ICOs, which have greater incentives to reduce costs across the care continuum, but this must be confirmed through further data-driven evaluation. There is also the need to consider and examine the potential risks and unintended consequences (e.g. increasing caregiver personal and financial burden; increasing out of pocket costs for care; confidentiality and privacy with technology use; safety and reduced quality of care by poorly trained providers) of the paradigm shift to HBDC.

We therefore put forth a set of key consensus recommendations. As detailed in Table 3, the panel strongly believes and advocates for the home to be considered as the nexus of care. In this context, new payment models are needed to support home care practices and reward integration of care and a diverse new workforce that spans long term care services and supports should be developed and prepared urgently. Further, the home provides a prime opportunity for the testing, integration, and deployment of new technologies to promote communication, monitoring and safety, and symptoms management. Finally, it is clear that dissemination of home-based care practices will not happen easily---it must be supported by intervention development and testing stages, by explicitly considering perceived value from key stakeholders, variations in local priorities and resources, and clear communication and dissemination of research results and value propositions to stakeholders about the need and benefits of HBDC promote demand and uptake of evidence-based dementia services. These recommendations provide a framework to chart a course forward for setting specific targets and timelines and will hopefully guide NAPA, and development of local and national Alzheimer's plans. In conclusion, as new models of person- and family-centered dementia care paradigms emerge, now is the time to rethink how the home can serve as the nexus of care for addressing medical, social, emotional, and cultural needs.

Acknowledgments

We wish to acknowledge Elizabeth Tracey (scientific writer) for assistance in project organization and in preparing this consensus panel report.

This work was supported by the BrightFocus Foundation [Grant# CA2016637]; National Institutes of Health [Grant # R01AG046274]; Centers for Medicare and Medicaid [Grant# 1C1CMS331332].

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Abbreviations

HBDC	Home-based dementia care
ICOs	Integrated Care Organizations
ACOs	Accountable Care Organizations
PCORI	Patient Centered Outcomes Research Institute
NAPA	National Alzheimer's Plan Project

Research in Context

Strategic planning at local, national, and global levels is underway to address the dementia crisis. Among a host of issues, these plans must consider a wide range of issues: treatment development and research; timely diagnosis; care delivery, health system design, and service financing; quality of care and consumer preferences; workforce development; and public education and awareness. This paper seeks to make a substantive contribution to this dementia care strategic planning by presenting findings and recommendations of a national multidisciplinary expert panel focused on the importance, opportunities, and barriers related to shifting the clinical practice paradigm to focus on home-based dementia care.

Highlights

1. Home-based dementia care should be considered the nexus of new long term care models
2. New payment models are needed to stimulate, reward, and support home care practices
3. A skilled new workforce spanning long term care needs to be developed and equipped
4. New technologies to promote best practices must be tested, integrated and deployed
5. More effective development of value, understanding of competing local priorities and adaption, and improved communication about home-based care are needed

Table 1

Principles Guiding Comprehensive Dementia Care at Home

- Delivery of high value care
  - Practices that are evidence-based and/or evidence informed
  - Seamless from time of diagnosis to end-of-life including bereavement
- Needs based (e.g., unmet needs, needs prioritized by families, caregiver identified needs)
- Therapeutics, practices, strategies tailored to needs, values, beliefs, practices of families
- Access to information, strategies, therapeutics when needed and as needed
- Caregiver-and person with dementia centered care provision
  - Purposeful engagement in decision making
  - Considered as active members of the treatment team

Table 2
Key areas of focus for dementia competent workforce development

Recommendation	Rationale/outcome
• Increasing the salaries to a living wage, and providing acceptable benefits	• Alleviation of high turnover rates and constant costs for hiring and retraining by employer • Greater consistency in healthcare workers may lead to better outcomes for patients and families, and workers themselves
• Providing better supervision and training	• Reduce the high rates of workforce turnover and injury • Improve quality of healthcare delivered, and increase the safety of both workers and families reduce need for heavy reliance on “on-the-job” training
• Greater availability of online training courses offered by academic institutions, government agencies, and/or nonprofit organizations	• Increase access to certification programs • Increase public awareness and education, and market demand for high quality services through online courses developed for family caregivers that can be accessed at low cast and from home.
• Focus on inclusion and preparation of diverse and new worker types	• Shortages in specialty providers such as geriatric medicine and geriatric psychiatry physicians, nurse practitioners, and social workers render any model obsolete and impractical if the care models require such specialists. • Focus on staffing new models with providers who can be quickly trained or who are already in great supply [65]. • Hiring and training a diverse workforce from various cultural and professional backgrounds will help to keep pace with the increasingly diverse aging population whom they will serve. • Greater opportunity for cultural tailoring of services
• Increased investment and development of “learning laboratories” to foster workforce dementia competent skills.	• In-person interactive training that involves a learning laboratory and includes a mixture of didactic sessions, hands on practicum, live person support, audit and feedback, and recertification opportunities likely offers the best training experience
• Focus on developing workforce trained in multidisciplinary team-based care	• Team based care supports best dementia care practice and should focus on team member accountability, acculturation of team members, effective communication, and referral and triage.
• Provide more incentives to employers to recruit and adequately train a diverse workforce	• Increase reimbursement policies for major health insurers to include social and non-medical supportive care, environmental modifications • Provide health system administrators and community agencies with the resources to adequately train the new workforce

Table 3
BrightFocus Panel Core Recommendations

Core recommendations
New models of long term care and support that centers around the home as the nexus of care from diagnosis to end of life, integrating medical, social, emotional, environmental and supportive care must be prioritized for dementia into the future
New payment models to support effective evidence-based home care practices and that stimulate and reward integration of care across acute and long-term services and supports needs further development and testing and policy reform.
Development and preparation of a dementia competent workforce to offer a range of home-based care services is critically needed and could be supported by addressing key issues related to employee retention including increasing salaries, better supervision, more flexible, continuous and engaging training, creation of “credentialing” for skilled workers along with pathways for promotion, team-based care, and rewarding high quality care.
New and existing technologies to link families to care providers and share information more efficiently, monitor and promote home safety, monitor health and symptoms status, and deliver care strategies, care management, and treatments must be fully evaluated and tested, deployed and utilized.
To address barriers to dissemination of home-based dementia care including absence of a coherent national approach to payment for home based care, cultural factors, and lack of understanding of the long term value of home based dementia care, a major priority of the field should be considering perceived value, variations in local priorities and resources, and adaptation to promote greater and more effective communication about the need and benefits of home-based dementia care must to stakeholders