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Integrating Care for Older Adults with Cognitive Impairment

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Abstract

The number of older adults with Alzheimer's disease and related disorders is expected to triple over the next 50 years. While we may be on the cusp of important therapeutic advances, such advances will not alter the disease course for millions of persons already affected. Hoping for technology to spare the health care system from the need to care for older adults with dementia is no longer tenable. Most older adults with dementia will receive their medical care in the primary care setting and this setting is not prepared to provide for the complex care needs of these vulnerable elders. With an increasing emphasis on earlier diagnosis of dementia, primary care in particular will come under increasing strain from this new care responsibility. While primary care may remain the hub of care for older adults, it cannot and should not be the whole of care. We need to design and test new models of care that integrate the larger health care system including medical care as well as community and family resources.

The purpose of this paper to describe the current health care infrastructure with an emphasis on the role of primary care in providing care for older adults with dementia. We summarize recent innovative models of care seeking to provide an integrated and coordinated system of care for older adults with dementia. We present the case for a more aggressive agenda to improving our system of care for older adults with dementia through greater training, integration, and collaboration of care providers. This requires investments in the design and testing of an improved infrastructure for care that matches our national investment in the search for cure.

INTRODUCTION

Research, policy, and advocacy addressing the needs of older adults with Alzheimer's disease and their families is as fragmented as the health care industry that seeks to provide care for these vulnerable elders [1–3]. At least some of this fragmentation is explained by the need to focus on a simplified list of issues in order to limit complexity. While reductionism in basic science is common, it is also found in approaches to clinical care, policy, and advocacy. This focused approach has produced results in some respects, but it also tends to undervalue and under-resource more integrated and comprehensive approaches.

We argue that there is an imbalance in the US approach to care for older adults with dementia and this imbalance has resulted in a health care industry unprepared to meet the care needs of older adults with dementia [1, 4–6]. Research, policy, and advocacy for Alzheimer’s disease are quickly moving toward greater investment in primary prevention. This is an important development. However, this effort needs to be matched by a parallel investment in the symptomatic management and care of older adults with Alzheimer’s disease.

We need to construct a more integrated and comprehensive approach to care for Alzheimer’s disease for at least five reasons. First, although Alzheimer’s disease is the most recognized dementia syndrome, “Alzheimer’s” has become a sound bite for a wide range of overlapping and disparate conditions presenting with cognitive impairment. With the logical advent of interest in prevention and earlier recognition of dementia, [7] the heterogeneity and size of the population of older adults in potential need of care for impaired cognition has significantly expanded [8, 9]. The second reason to invigorate a focus on integrated care is the reality that most dementia syndromes are incurable, progressive, debilitating, and ultimately terminal conditions [1, 10]. Because of this, they place huge demands on health care and community resources [11, 12]. Third, most older adults with dementia suffer from multiple chronic conditions and many will die from chronic conditions other than the dementing illness [13–16]. Fourth, dementia syndromes compound the demand for health care resources through morbidity among individuals with the syndrome as well as morbidity among their family caregivers [17–19]. Fifth, the initial advances in the treatment of Alzheimer’s disease and related dementias may improve survival but also increase the length of time that an older adults needs care. This may paradoxically place an even greater burden on those components of the care system charged with providing this care.

Taken together, these five features result in a large and growing need to provide humane and dignified longitudinal care for a population that already exceeds 3–4 million people [20, 21]. While demographers often speak in terms of projections, it is important to highlight that the care needs for these patients are neither hypothetical nor distant. There is no longer any reason to believe that technological advances will spare the nation from the need to provide care for this population. Sloane and colleagues have estimated the growth in the number of patients with Alzheimer’s disease in the next fifty years even under optimistic scenarios of prevention and treatment efficacy. The authors concluded that: “None of our models predicts less than a threefold rise in the total number of persons with Alzheimer’s disease between 2000 and 2050.”[21] This translates to a population of 6–12 million people with Alzheimer’s disease and related dementias who will strain the nation’s resources even if optimism for the impact of new treatments is justified [21].

One appropriate response to the epidemic of dementia is to search for prevention, cure, and treatment strategies [22–24]. However, another appropriate response is to prepare the health care system and the community to provide care for these patients. In essence, this is a response that hopes for the best but prepares for the worst. The purpose of this paper to describe the current health care infrastructure with an emphasis on the role of primary care in providing care for older adults with dementia. We then summarize recent innovative models of care seeking to integrate care for older adults with dementia across the continuum of care.

REALITIES OF THE CURRENT HEALTH CARE INFRASTRUCTURE

More than 30 years ago, the World Health Organization defined primary care as:

“Essential health care, based on practical, scientifically sound, socially acceptable methods and technology, made universally accessible to individuals and families in the community,

through their full participation and at a cost the community and the country can afford. It forms an integral part of both the country's health system, of which it is the central function and main focus, and of the overall social and economic development of the community.”

In countries with and without national health care systems and across multiple different organizational structures, primary care often falls short of this ideal. Primary care rarely achieves integration with other important social and economic developments in the community. Researchers have repeatedly documented quality gaps in primary care across a broad range of conditions [25, 26]. With the increasing emphasis on chronic care and prevention, it is now clear that there is not enough time in the day for primary care providers to deliver guideline-level care [27, 28]. Nonetheless, most older adults in the US and other developed countries receive their care in primary care settings and this is where quality improvement must begin [4, 29].

From a workforce perspective, ambulatory care by primary care physicians constitutes the major infrastructure element in care for older adults [30, 31]. There are about 175,000 primary care physicians in the United States compared with fewer than 10,000 adult neurologists, less than 8,000 geriatric medicine physicians, and about 1600 geriatric psychiatrists [4, 32, 33]. These numbers fall far short of projected need; the American Geriatrics Society has projected a need for 36,000 geriatric medicine physicians alone [4]. In addition to low numbers of physicians with specialty training in the diagnosis and management of dementia, these providers are unevenly distributed across the country [4, 33]. To make these limited workforce issues more complex, one must recognize that not all of the providers within these sectors are truly expert in dementia care, that the different disciplines often focus on different aspects of dementia care, and that these different providers rarely work together in teams. Studies of ambulatory care services utilization among Medicare beneficiaries demonstrate that primary care physicians generate nearly half of the Medicare claims for older adults compared to less than 1% by geriatric medicine physicians [30]. Even among medically complex older adults, primary care physicians often remain the main provider [34, 35]. In addition, primary care is currently more prepared than specialty settings to manage multiple comorbid conditions. Care management strategies that allow for care of the patient rather than an individual disease are often more effective and efficient [31, 36–38].

Unfortunately, the current quality of care in primary care for older adults with dementia is poor. Two thirds of dementia cases may remain undetected in primary care settings [39, 40]. In a typical primary care physician's practice, perhaps less than a dozen older adults would be recognized and treated for dementia [41]. If a primary care physician had a panel of approximately 1500 patients and 40% of these patients were age 65 and older ($n=600$) and 5% of these patients had dementia ($n=30$), only half ($n=15$) would likely be diagnosed and then less than half would be offered and accept treatment ($n=7$). In primary care, less than 50% of patients with moderate to severe cognitive impairment receive the recommended evaluation and very few of these patients are seen by neurology or psychiatry. Also, 22% of those with moderate to severe impairment are prescribed medications with anticholinergic side effects or major tranquilizers [14].

In expanding the framework of care beyond the medical care infrastructure to the larger health care infrastructure, care of older adults with dementia must account for other health care professionals and direct care workers as well as informal (family) caregivers [4, 42]. We must also recognize that the magnitude of informal caregiving is so substantial that it affects the entire US workforce. According to a 2003 report from the National Alliance for Caregiving, about one in five adult Americans provided unpaid care to another adult American. According to the National Alliance for Caregiving findings, one quarter of

caregivers helping someone age 50 or older reports the person they care for is suffering from dementia or other mental confusion [43]. The economic value of this “unpaid” informal care system is nearly double the entire federal expenditure for “paid” formal home care and nursing home care combined. The lost productivity of caregivers cost employers an estimated \$33.6 billion in 2004 [44]. Beyond the economic costs, prior research has established that many caregivers pay a penalty in terms of their own health, including excess mortality [18, 45]. Caregivers’ availability in the community, either formal or informal, is a major determinant in the likelihood and timing of long-term care placements [46–49]. Unfortunately, 90% of older adults with dementia will be institutionalized prior to death [47, 50]. Because the cost of institutionalized care now accounts for nearly 30% of Medicaid expenditures, policy making at the state level is heavily influenced by care decisions for older adults.

Taken together, the workforce realities and the importance of managing multiple chronic medical conditions in an ambulatory care setting render primary care the main infrastructure component to provide care to older adults with dementia. While primary care may serve as the hub of care, it is not sufficient alone to provide excellent care [6]. Specialist care is clearly an integral part of medical care for older patients.⁴ Indeed, half of older adults’ physician visits are to specialists and nearly all older adults report seeing multiple physicians in a given year [4]. These providers are distributed across multiple sites of care including ambulatory care, hospitals, post-acute care, and long-term care among other sites. Equally important is the role of community-agencies, direct care workers, and family caregivers. We currently lack a system of care that would help coordinate all of these providers across the continuum of care for older adults with dementia.

It is important to recognize that the health system redesign issues relevant for older adults with dementia are also relevant for other chronic medical conditions. Primary care is not well-designed to support chronic care management. Even for common chronic conditions such as hypertension, diabetes, or depression, where effective diagnosis and treatment recommendations are more established, most patients do not receive an adequate dose or duration of therapy [51–55]. For example, only about one-third of patients diagnosed with hypertension reach therapeutic targets despite the availability of effective screening, diagnosis and treatment approaches [56]. One can reasonably expect greater problems in delivering guideline-level care for older adults with cognitive impairment where the screening, diagnosis, and treatment recommendations are more controversial [40, 41, 57–64].

There are several lessons to learn from prior research on practice improvement for other chronic conditions in primary care. First, recognition and diagnosis are necessary but not sufficient to improve patient outcomes and advances in diagnostics tend to outpace advances in treatment [65]. For example, simple and effective depression screening and diagnosis aids for use in primary care have been available for decades. However, routine screening for depression in primary care is not recommended unless the practice has the systems in place to support guideline level care following a positive screen [66, 67]. Second, primary care providers may, in some instances, need improvements in knowledge, but the main problem is poorly designed systems of care [68, 69]. Third, there are examples of improved patient outcomes for chronic conditions, mental health conditions, and geriatric syndromes with the innovative application of new models of primary care [38, 52, 70–74]. In general, these effective models contain one or more features of the chronic care model including: “self-management support, clinical information systems, delivery system redesign, decision support, health care organization, and community resources” [52]. For older adults in particular, key features of these models also highlight personalized team care to match each patient’s goals, values, and resources [4]. Establishing goals of care is especially relevant for

older adults, including older adults with progressive dementia [1, 10]. We now turn to a description of innovative models of care that attempt to implement one or more of these features.

NEW MODELS OF CARE FOR OLDER ADULTS WITH DEMENTIA

Each of the studies described below can properly be described as multi-faceted. However, none of these studies was designed to deliver an integrated intervention with strengths across the full spectrum of community, caregiver, or medical care targets. In addition, we have not attempted to provide a complete accounting of the literature on new models of care but rather examples of studies that focus on improving the quality of care through systems-level interventions.

Mittleman *et al.* conducted a clinical trial to determine the effectiveness of comprehensive support and counseling program for spouse-caregivers and their families [75–77]. The intervention was designed to postpone or prevent nursing home placement of patients with Alzheimer’s disease. The investigators enrolled a volunteer sample of 206 spouse-caregivers of Alzheimer’s disease patients who were provided with 6 sessions of individual and family counseling within 4 months of enrollment in the study. These subjects also were required to join support groups. Nursing home placement was delayed 1.5 years among the intervention group and this delay in nursing home placement was not at the expense of the caregiver’s mental health [77]. The Mittelman study is notable because it remains one of the few interventions that resulted in delay in nursing home placement. The Medicare Alzheimer’s Disease Demonstration Project was designed to improve caregiver outcomes through case management and subsidized community services and thereby decrease the nursing home entry rate of patients in the intervention group compared to controls [78, 79]. Over 5,300 volunteer applicants to the demonstration program and their caregivers were randomized. The investigators were unable to demonstrate substantial reductions in caregiver burden, caregiver depression, or nursing home placement. The authors suggested that the intervention strategy needed to include coordination with primary care and chronic disease management. The Resources for Enhancing Alzheimer’s Caregiver Health (REACH) study took an approach similar to the Mittelman *et al.* studies in focusing on the family caregiver [80–83]. REACH recruitment was conducted at memory disorder clinics, primary care clinics, social service agencies, physician offices, churches, and community centers. The core intervention was providing the caregivers with access to a trained interventionist who functioned as a coach. The intervention allowed tailoring of components to the needs of each caregiver and emphasized self-empowerment. The REACH intervention resulted in meaningful improvements in quality of life for caregivers but did not result in delays in institutionalization [83].

Vickrey *et al.* tested a guideline-based, comprehensive dementia care management intervention in a clinic-level, cluster randomized, controlled trial [84–86]. This intervention is arguably the most comprehensive care management approach to dementia care tested to date. Most of the subjects were enrolled in a managed Medicare program and were identified through claims data. The 12-month intervention emphasized linkages with community resources and multi-agency coordination through a dementia care manager. The study included 18 primary care clinics and 408 patients with dementia age 65 years or older and their 408 informal caregivers. Patients with dementia and their caregivers were assigned a care manager who worked with and trained the caregiver, prioritized patient and caregiver needs, and recommended interventions to health care and community service providers. This care manager also functioned as an important bridge between the health care system and local community service agencies and had access to an internet-based care management system. The care manager conducted a structured in-home assessment and, guided by a

comprehensive care management manual, could choose from a menu of recommended care plans and referrals tailored for the individual subject. Although the care manager could not directly order tests or medications for example, they did communicate recommendations to the subject's primary care physician. In addition, the internet-based care management system allowed direct referral to community agencies and sharing of patient information as appropriate.

Quality of care, as measured by adherence to guidelines, was dramatically higher in patients who received the intervention (64% vs. 33%). Patient quality of life improved, and caregivers reported improved social support, mastery of caregiving, and confidence. Caregiver quality of life did not differ between the experimental groups and the study did not directly measure patient outcomes such as behavioral problems, cognition, or time to nursing home placement.

Our research team designed a collaborative care intervention based on current treatment recommendations to improve the recognition and treatment of Alzheimer's disease in primary care.⁷³ We completed a controlled clinical trial of 153 older adults with Alzheimer's disease and their caregivers who were randomized by physician to receive collaborative care management versus augmented usual care [73]. Both study groups completed a counseling visit with an advanced practice nurse who provided education about Alzheimer's disease and referral to community resources. Over the following year, intervention patients received care management by an interdisciplinary team led by a nurse practitioner working with the patient's family caregiver [87]. In addition to consideration for treatment with cholinesterase inhibitors, the team used standard protocols to identify, monitor, and treat behavioral and psychological symptoms of dementia. These guidelines stressed non-pharmacologic management.

Initiated by caregivers' reports, 89% of intervention patients triggered at least one protocol for behavioral problems with a mean of four per patient from a total of eight possible. Intervention patients were more likely to receive cholinesterase inhibitors and antidepressants but there were no group differences in prescriptions for antipsychotics or sedative-hypnotics. Intervention subjects were more likely to rate their primary care as very good or excellent. Intervention patients had significantly fewer behavioral symptoms at 12 months. Intervention caregivers also reported significant improvements in distress and depression. There were no group differences in mean scores on cognition, activities of daily living, or rates of hospitalization or nursing home placement or death. Thus, collaborative care for the treatment of Alzheimer disease resulted in significant improvement in the quality of care and in behavioral disturbances among primary care patients and their caregivers [73].

New models of care also have been developed to improve end-of-life care for older adults with dementia. The Palliative Excellence in Alzheimer Care Efforts (PEACE) Program took a disease management approach that attempted to integrate palliative care into the ongoing primary care of patients with dementia from diagnosis to death [74]. Key elements of the program were advance planning, patient-centered care, family support and education, efforts to uncover unmet needs and uncontrolled symptoms, and eventual referral to hospice. Much of the intervention was coordinated through a nurse with special training and support from geriatric medicine physicians. Results of PEACE included high caregiver satisfaction, excellent symptom detection and management, high rates of hospice enrollment, and high likelihood of patient death occurring at home [88–90]. Notably, this intervention was coordinated through a geriatric medicine-led memory clinic capable of providing both consultative care and primary care. This hybrid approach to memory care clinics may foreshadow future models of care where older adults who reach later stages of dementia are

more appropriately cared for in specialty settings. This would be analogous to patients with end-stage renal disease transferring care to nephrologists when dialysis is initiated.

CONCLUSIONS

The population of older adults with dementia will reach 10 million in the coming decades. These older adults have complex care needs that may span ten years or more and require coordinated efforts among multiple physicians, direct care workers, informal caregivers, and multiple sites of care including community agencies as well as the home. The US health care system is not currently prepared to provide this high-level of integrated care. Technological advances in pharmaceuticals and other interventions will not spare the nation the need to provide hands-on care for millions of persons with Alzheimer's disease and related dementias [21]. While primary care is the main infrastructure component to provide care for older adults with dementia, it is a hub of care and not the whole of care. Primary care physicians already have too little time to provide guideline-level chronic disease and preventive care. In addition, primary care practices are severely limited in terms of physical space. Most primary care practices would not be able to accommodate a cadre of care managers in terms of providing them space to deliver patient care for a variety of individual chronic medical conditions. For this reason, improving the care system for older adults with dementia equates to bringing additional resources to bear in the primary care setting or expanding primary care beyond the ambulatory clinic setting and primary care physicians, or better identifying which patients would benefit from specialty care.

The workforce needed to provide care across the continuum of care is much broader than physicians with specialty training in dementia care. Expansion of the future work force must also include nursing, social work, pharmacists, mental health workers, family caregivers, and other direct care workers [4]. In order to allow families to care for loved ones with dementia in their homes for a longer period of time, we also need to increase support for self-management. This is an area where technology may have a great deal to add but it will not substitute for hands-on care. The majority of hands-on care will continue to be delivered by informal caregivers.

In assessing the current deficiencies of the US health care system relevant to the needs of older adults with dementia, there are clearly limitations in the knowledge base and the effectiveness of treatments. Unfortunately, the knowledge that is available is not being effectively implemented. Thus, we find limitations in the health care workforce in terms of available expertise, diversity, distribution, and their established roles or scope of practice. We find limitations in the health care infrastructure in terms of the physical limitations of primary care, fragmentation of care across specialties and sites of care, inadequate information technology, and mismatched reimbursement schemes all of which present barriers to team-based care. We find poor integration of family caregivers, direct care workers, and community service agencies with the formal medical care system. Early research has demonstrated that new models of care can overcome some of these limitations, but they require system-level changes that are often beyond the reach of the typical small primary care practice.

In terms of next steps, there are several areas where future research and dissemination would be fruitful. First, Medicare and other payors have begun discussing how they might support care coordination, team-care, and other components of the medical home. While removing financial disincentives to care coordination would be a welcomed initial step, implementing these models will require much more than changes in payment schemes [91]. Second, primary care physicians still face great uncertainty regarding which older adults with cognitive impairment need which care and by whom. Care guidelines often taken as

“standard of care” by specialty dementia providers are nonetheless still highly controversial in primary care. These controversies range from the value of screening to the value of treatment to the role and timing of palliative care. We need much better agreement among providers and experts on what constitutes the right care for the right patient at the right cost if we want to implement systematic change in care. These system level changes will require continued efforts to improve communication and improve coordination across multiple providers and sites of care, including the family caregivers and the community agencies that support them. Finally, we have not yet tested models of care that more closely approach the health care system’s response to comprehensive care for end-stage renal disease or cancer, for example. We need to design and test the value of specialty dementia clinics that provide comprehensive and coordinated care for the subset of older adults with dementia who have care needs that are beyond the scope of primary care. Such a comprehensive approach will require that these special clinics move well beyond a singular focus on medical treatment of dementia and instead focus on providing care for older adults with dementia and their family caregivers.

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