

Growing Role of Home-Based Primary Care for Individuals with Dementia

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ABSTRACT

There is an increasing need for home-based primary care (HBPC) because of the growing number of individuals with dementia who are homebound. From the years 2010 to 2013, the cost of providing care to older adults with dementia in the US has increased from \$109 billion to \$220 billion. This article gives an overview of HBPC, the benefits of HBPC, and the barriers to the provision of HBPC in the current health payment structures. An overview of national strategies for future steps and suggestions to improve upon HBPC are also reviewed.

Keywords: home-based primary care, dementia, home care, homebound, caregiver, nurse practitioner, older adult

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INTRODUCTION

In their most recent strategic plan, the US Department of Health and Human Service calls for strategies to improve individual access to quality health care, while still controlling health care costs.¹ In 2010, the US spent \$109 billion on dementia care, which increased to \$220 billion in 2013, exceeding monies spent on cancer and heart disease combined.^{2,3} The average age of death in the United States has also steadily increased over the last 10 years, as has the rates of other chronic diseases. Home-based services for health care has been proposed by the Agency for Healthcare Research and Quality as an alternative way to provide care and address the preferences and needs of homebound, chronically ill individuals.⁴ However, less than 12% of individuals who identify themselves as homebound report receiving home-based primary care (HBPC) services.⁵

Homebound status is defined by Medicare as being unable to leave one's home without the help of another person or medical equipment because of illness or injury.⁶ A Medicare criterion also states that leaving home must cause considerable and taxing effort for the individual.⁶ Others have defined homebound as someone who leaves the house less than one time per week.⁷ Currently, over 1 million people meet the definition of homebound, most of

whom are frail, older individuals.^{7,8} Such individuals account for 29% of Medicare Part A and B costs, 46% Medicare admissions, 23% annual mortality, and 24% of Medicare hospitalizations.⁹ Being homebound is also associated with loneliness, multiple comorbidities, increased risk of hospitalization, and worse self-reported health status.^{7,9}

Many individuals who meet the definition of homebound are also cognitively impaired as a result of dementia. Over 5 million individuals in the US have dementia, with a projected growth to exceed 16 million in 2050.^{3,10-12} Dementia is the sixth leading cause of death in the US, as well as a leading cause of disability and poor health.¹⁰ These individuals suffer from multiple comorbidities and eventually become homebound. Dementia is also reported to be one of the costliest health conditions to American society.

OVERVIEW

Travel to a traditional office visit can be challenging for older adults who have dementia because of functional and mental impairments. They may choose to forgo traditional office care and instead go to an emergency department for episodic care.⁸ Thus, not only are they at risk of lacking consistent primary care, they are also at higher risk for further functional decline and early, permanent institutionalization.⁸ Individuals with dementia have three times as many hospital stays as

other people their age.^{10,13} Missing regular medical care for these individuals can lead to a cascade of worsening disease states and acute health crises.⁸

The goals of most HBPC programs are to maximize an individual's function, quality of life, and independence at home while also providing high-quality health care.⁸ Independence at Home, a demonstration project created by the Affordable Care Act, has tested whether providing medical care at home improves health outcomes and cost of care for frail individuals with complex health needs. On average, participating practices have seen a 7.7% savings (or \$3,070) per beneficiary in the first year. Most savings appear to be related to preventing hospitalizations.⁵

HBPC exemplifies patient-centered care because it helps to foster trust between the provider and the patient. This trust then helps to uncover other situations that might be influencing the health of the individual, such as unsafe housing, inadequate nutrition, caregiver stress, or poor management of medications.⁵ Such situations may be difficult or impossible to discover within a traditional office setting, and require the provider to know both the patients and their environments.¹⁴

TRADITIONAL OFFICE BASED CARE OF DEMENTIA

Primary care provided to individuals with dementia is poor; quality indicators for dementia are being met only between 18%–42% of the time in traditional office settings¹³ (see Table^{19,20}). Individuals with dementia frequently have other co-morbidities that require time-intensive counseling and safety discussions that cannot occur in a 15- to 20-minute office visit.¹⁰ Also, many primary care physicians have panels that do not include a large number of dementia patients and may lack expertise in diagnosing and treating the nuances of dementia. Caregivers of dementia patients also require time and counseling, needing referrals to social supports and coordinated referrals to community organizations. To appropriately meet the needs of both the patient and caregiver, the provider must have time to listen to their concerns and counsel them appropriately.

Challenges related to transportation may also be barriers to appropriate care for those with dementia. Many individuals with dementia have diminished

physical and cognitive function, making transportation to a clinic visit difficult.^{3,9} These individuals become reliant on family, friends, and paid social services for transportation and to accompany them to their office visit.²¹ In a descriptive study by Fowler and Kim,³ caregivers of individuals who have dementia reported various reasons that traditional office settings were not meeting the needs of their loved ones with dementia. Issues related to transportation, unwanted behaviors of loved one when out of their accustomed environment, and finding competent providers were noted as barriers.

HOME BASED PRIMARY CARE

Attributes of HBPC

HBPC tends to be more holistic than a traditional office visit. The providers in HBPC tend to focus on not only the patient's medical conditions, but also on elements that influence those conditions, such as caregiver health, environment, nutrition, function, and mental health.⁵ Typical home visits last for about an hour, and usually include caregivers in care-related conversations. Visits are performed based on need; they may occur every 4–6 weeks for stable patients, but sometimes daily for acute needs.⁵ The provider typically sees around 9 patients per day, allowing more time to communicate with patients and their caregivers, discuss the patient's tolerance of medications and treatments, and observe the home situation.^{5,15} By providing care in the patient's home, the provider is in a unique position to actively assist the patients and caregivers transition between care settings as needed, and help improve communication between inpatient and outpatient providers. HBPC allows for the provider to call on community resources as needed to support care of those with dementia in their homes.

Characteristics of successful HBPC programs include scheduled interdisciplinary meetings; including essential members of the patient care team such as physicians, nurse practitioners, social workers, physical and occupational therapists, behavioral health specialists, and nurses. The literature suggests that the success of a HBPC program largely depends on the inclusion of these components: behavioral health and social support; 24-hour telephone access for urgent care, with efficient response to needs;

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