The Invisible Homebound: Setting Quality-Of-Care Standards For Home-Based Primary And Palliative Care

ABSTRACT Approximately four million adults in the United States are homebound, and many of them cannot access office-based primary care. Home-based medical care can improve outcomes and reduce health care costs, but this care operates in a quality measurement desert, having been largely left out of the national conversation on care quality. To address this shortcoming, two of the authors created the National Home-Based Primary and Palliative Care Network, an organization whose members include exemplary home-based medical practices, professional societies, and patient advocacy groups. This article describes the current status of home-based medical care in the United States and offers a brief narrative of a fictional homebound patient and the health events and fragmented care she faces. The article then describes the network’s quality-of-care framework, which includes ten quality-of-care domains, thirty-two standards, and twenty quality indicators that are being tested in the field. The same two authors also developed a practice-based registry that will be used for quality-of-care benchmarking, practice-based quality improvement, performance reporting, and comparative effectiveness research. Together, these steps should help bring home-based medical care further into the mainstream of US health care.

Approximately four million vulnerable adults in the United States have difficulty obtaining or are completely unable to access office-based primary care because they are frail, functionally limited, and homebound. They are among the most costly patients in the US health care system, not because of a specific disease but because of a powerful combination of multiple chronic conditions, functional impairment, frailty, and social stressors. The full scope of their needs is not met by any of the existing formal health services—ambulatory, hospital, emergency department (ED), hospice, or skilled home health care. Their needs and their limited ability to access primary care commonly result in unnecessary ED visits, hospitalizations, and downstream health care expenditures. These patients account for approximately half of the costliest 5 percent of patients.

Sending patients with complex chronic conditions through a fragmented, discontinuous system of health care is increasingly recognized as costly and wasteful to payers and harmful to patients. New ways to organize health service delivery and payment to address these issues are emerging under the Affordable Care Act. Home-based medical care, which encompasses both primary and palliative care, provides a mechanism for such patients to obtain ongoing
care in the community setting. In home-based primary care, patients ideally receive comprehensive longitudinal primary medical care at home from an interprofessional team of physicians, nurse practitioners, or both, together with nurses, social workers, and skilled therapists. In some cases, all team members are employees of a given practice. In other cases, practices may work collaboratively with home health agencies to provide skilled home health services, such as physical or occupational therapy or skilled nursing services on an episodic basis, for patients who qualify for them. Some programs, such as those operated by the Department of Veterans Affairs (VA), may also incorporate telehealth.

Home-based palliative care provides care in the home for people with serious illnesses and focuses on offering relief from the symptoms, pain, and stress of a serious illness. Its goal is to improve quality of life for patients and their families. Similar to home-based primary care, it is provided by a team of doctors, nurses, and other providers.

The focus of home-based primary or palliative care is on continuity of medical care over time. This is in sharp contrast to typical skilled home health care, which is ordered by a physician (who commonly never visits a patient at home) and is designed to provide skilled therapy or nursing services for a limited period of time to patients—for example, in the context of helping a patient after discharge from the hospital.

From 2000 to 2006 there was a 100 percent increase in the home-based medical care provided to Medicare beneficiaries. Approximately 1 million nonpodiatry home-based medical visits were provided in 2006 and 2.49 million in 2013. The number of home-based medical visits has increased rapidly, but the number of providers performing those visits has decreased markedly. This suggests that the health care providers delivering these services are focusing their practices on the services. It has been estimated that there are approximately 1,000 primary care providers (physician, osteopath, nurse practitioner, physician assistant) who perform home visits full time (at least 1,000 visits per year) (Constance Row, American Academy of Home Care Medicine, personal communication, December 10, 2014). A recent national survey of home-based primary care practices found substantial heterogeneity of practice types in terms of size, business models, provider types, and approaches to quality-of-care issues.

The rapid growth of home-based medical care is likely to continue, since the Affordable Care Act (ACA) creates strong incentives for financially at-risk organizations—such as accountable care organizations, Medicare Advantage plans, and Medicaid managed care plans—to incorporate home-based medical care into their population health strategies, with hopes of achieving the Triple Aim for health care.

Furthermore, the Independence at Home Demonstration, detailed in section 3024 of the ACA and managed by the Center for Medicare and Medicaid Innovation, is testing whether a shared savings approach can serve as a sustainable financial model for home-based medical care practices and can deliver high-quality care. Results from the demonstration are pending.

Despite the increasing use of home-based medical care, there is currently no quality-of-care framework or set of nationally recognized and widely used quality measures (or quality indicators—we use the two terms interchangeably) for home-based medical care practices. As a result, payers lack knowledge of the unique care needs of the population that could benefit from home-based medical care and of how such practices are designed. Payers also lack data to help them judge the quality of care provided by a practice.

Home-based medical care providers who are interested in benchmarking their own practices are forced to use available quality metrics, most of which are specific to a single disease. These generic measures for single conditions might create performance incentives to provide the wrong type of care for high-need and high-cost patients with multiple morbidities, who often have limited life expectancy.

Home-based medical practices also lack the infrastructure to engage with national performance reporting efforts. Under Physician Quality Reporting System payment adjustment regulations, this inability may soon result in serious financial penalties (a 2 percent payment adjustment) for these struggling home-based primary care practices.

With ongoing growth in home-based medical care, there is an inherent need to understand who should receive it and what represents quality of care for a homebound patient. The aims of this article are to describe the unique characteristics of homebound older adults, existing models of home-based medical care, the deficits of existing quality measures for homebound older adults who are cared for at home, and the development of a quality framework for this generally neglected but important population.

Alice: A Homebound Patient

The following narrative presents a fictional composite character, Alice, to illustrate the health events and care scenarios that homebound older adults typically confront. It is based on the authors’ clinical experiences with patients.
CHRONIC CONDITIONS AND FRAGMENTED CARE

Alice is an eighty-five-year-old former clerical worker whose two sons live in a different state. She lives alone, and her sole source of income is Social Security. Medicare is her primary health insurance. Alice’s income from Social Security is just above Medicaid eligibility requirements. She has long-standing chronic heart failure, type 2 diabetes mellitus, hypertension, chronic kidney disease, diabetic retinopathy, osteoarthritis, and depression.

For years Alice paid quarterly visits to her primary care physician at an ambulatory care clinic. As her arthritis and depression worsened, it became increasingly difficult for her to leave her home. As a result, she missed her scheduled primary care appointments but continued to call her physician’s office for prescription refills.

A year after her most recent visit to her primary care physician, Alice was hospitalized for a flare-up of heart failure and was then discharged home with Medicare Part A skilled home health care services that consisted of home nursing and physical therapy services, but no primary care medical services. Two weeks after her discharge, Alice was readmitted to the hospital for heart failure. This time she was discharged to a skilled nursing facility and then sent home with skilled home health care services.

Because of her functional impairments, Alice remained unable to see her primary care physician. Her recent hospitalizations resulted in accelerated functional decline: Walking around in her home became more difficult for her, and she had substantial difficulty with bathing and dressing. A neighbor brought her groceries, which consisted mostly of prepared foods that she could microwave. Her diabetes control deteriorated as a result of food insecurity, pain from her osteoarthritis, and worsening depression, which affected her physical activity and adherence to her medical regimen.

Alice remained too sick and functionally impaired to visit her primary care physician. Ironically, she was likely in greater need of medical attention than most of the patients that her physician saw on a given day. And there was an additional irony: From a care standpoint, Alice probably qualified for additional Medicare skilled home health services at this time. But because such services need to be ordered by a physician who sees a patient in a face-to-face clinical encounter, she could not receive them.

When Alice developed additional symptoms from her heart failure, diabetes, or other conditions, she called an ambulance to take her to the ED and was admitted to the hospital again. In the hospital, Alice was cared for by well-meaning providers, but they had limited knowledge of her medical conditions, goals of care, or care needs. A vicious cycle of repeated hospitalizations ensued, leading to further disability. Eventually, Alice was admitted to a nursing home.

Alice’s experience exemplifies that of millions of mostly homebound older adults in the United States.

HOMEBOUND: DEFINITIONS AND CHARACTERISTICS

The definition of homebound varies across studies, as have estimates of the size of the US homebound population. Medicare, for instance, uses its own definition to define eligibility for Medicare skilled home health services. The Medicare definition of homebound requires that a patient be “confined to the home.” That is, to leave the home the patient must need the aid of supportive devices or the assistance of other people or must have a condition that makes leaving the home medically contraindicated. In addition, there must exist a normal inability to leave home, and leaving home must require a considerable and taxing effort.

The Medicare definition may be too narrow to use as a definition of the population that may benefit from in-home medical services. Data from the US census suggest that as of 2006, over 4.3 million older adults could be classified as homebound.

Becoming homebound usually results from a combination of medical, psychiatric, functional, and social issues. The combination of these ingredients varies in any particular case. For many homebound people, a significant burden of multiple medical or psychiatric conditions, in some cases exacerbated by challenging social situations, results in functional impairments. In turn, these make accessing outpatient-based primary or specialty practices difficult or impossible. Some people can overcome the barriers with the assistance of helpful caregivers or purchased services. For others with limited social capital, such barriers result in their becoming homebound.

The presence of multiple chronic conditions and functional impairment among homebound people, especially older adults such as the fictional Alice, is common. Most homebound patients have multiple chronic conditions such as cardiovascular disease, diabetes mellitus, hypertension, and osteoarthritis, as well as other musculoskeletal diseases. A recent study demonstrated that over 70 percent of homebound patients had two or more chronic conditions.

Psychiatric and neurodegenerative conditions are also common, with dementia and depression particularly prevalent. A recent community-based study showed a 31 percent prevalence of depression and a 52 percent prevalence of dementia in homebound older adults. Functional...
limitations are common among homebound people with significant impairment in basic and instrumental activities of daily living.\textsuperscript{19} A significant proportion of this population needs palliative approaches to care but does not qualify for or is not yet ready to accept hospice services.

\textbf{Cut Off from Primary Care} Alice’s situation demonstrates the complex interactions between medical, functional, and social elements and how those elements could combine to result in an inability to obtain usual ambulatory-based care. Ultimately, Alice’s only access to care came through the use of emergency medical services, which resulted in her receiving increasingly fragmented care in the parts of the health care delivery system with the highest cost.

Furthermore, functional disability is associated with increased costs for Medicare beneficiaries. Among beneficiaries with three or more chronic conditions, those with functional limitations average about twice the annual per capita health costs compared with those without functional limitations.\textsuperscript{20}

As the number of older adults increases because of the aging of the baby-boom generation, the population of homebound older adults will also continue to grow. Homebound patients, as highlighted above, are expensive to care for. Between 2014 and 2019 Medicare skilled home health care costs alone are expected to rise from $77.9 billion to $124.5 billion.\textsuperscript{21}

Care costs for those with chronic conditions and functional limitations tend to be persistently high over time. In a recent analysis of data from the 2011 Medical Expenditure Panel Survey, 40 percent of people with the top 5 percent of health costs had elevated costs over multiple years and were likely to be characterized by multiple chronic conditions and functional limitations.\textsuperscript{22} These people need palliative care approaches and longitudinal medical care in the home.

\textbf{Models of Home-Based Primary and Palliative Care} For homebound patients, traditional ambulatory primary care is uncoordinated, inaccessible, and ineffective. However, home-based approaches can meet the care needs of such patients. Diverse in scope, size, and practice styles, home-based medical practices range from solo physicians and small group practices that take care of a few hundred patients to corporate practices that span several states and care for tens of thousands of patients.

A recent national survey of 272 non-VA home-based primary care practices found a mean average daily census of 457 patients with a median of 100 patients; the largest practice had a daily census of 30,972 patients. Eighty-eight percent of the practices offered 24/7 coverage for urgent patient concerns. Sixty percent held regularly scheduled team meetings to discuss specific patients, and 89 percent used an electronic health record. Only one-third of the practices used a defined quality improvement process.\textsuperscript{8}

High-performing home-based medical practices have redesigned care delivery to attend to the medical, functional, and social needs of their patients and caregivers in their homes. These practices have physicians, nurse practitioners, and physician assistants working in interdisciplinary care teams with social workers, mental health providers, and skilled therapists. The practices provide care coordination and case management services and thus give extraordinary continuity of care and can respond to new problems rapidly. We next describe two exemplary practices: the VA Home-Based Primary Care program and the MedStar Washington Hospital Center House Call program.

\textbf{VA Home-Based Primary Care} The VA Home-Based Primary Care program, established in 1972, delivers comprehensive primary and palliative care in the patient’s home for people who are “too sick to go to clinic.” The program provides comprehensive interdisciplinary care and targets patients with complex chronic diseases and functional impairments; nearly half of the patients need help with two or more of the five basic activities of daily living (bathing, dressing, eating, using the toilet, and transferring into or out of a bed or chair). The VA engages in regular quality audits of the program.

Each core team consists of a physician, social worker, rehabilitatation therapist, pharmacist, dietitian, psychologist, nurses, and nurse practitioners, all of whom have clearly delineated roles.\textsuperscript{23} Palliative care principles are systematically integrated into care provision. Strategic investment by the VA has allowed its home-based primary care teams to expand to 141 separate sites, with an average daily census of 33,000 patients nationally.

The underlying evidence base for the VA Home-Based Primary Care program is robust. A 2002 VA study of 11,334 veterans that compared their health care costs in the six months before they enrolled in home-based primary care with the costs in the six months following enrollment found a 62 percent reduction in hospital bed days, an 88 percent reduction in nursing home bed days, a 24 percent reduction in total VA costs of care, and a 264 percent increase in home care visits. Data from the program in 2007 demonstrated results similar to the 2002 study,
as well as a 21 percent decrease in thirty-day hospital readmissions in 2007.23

In the most recently reported data from the VA, Thomas Edes and coauthors studied 9,425 newly enrolled home-based primary care patients in fiscal year 2006.24 Cost analyses using concurrent modeled costs based on Hierarchical Condition Categories were employed. (This methodology is similar to methods employed by the Centers for Medicare and Medicaid Services [CMS] to make cost projections for the Program of All-Inclusive Care for the Elderly and for Medicare Advantage plans.) The investigators found that during use of the VA Home-Based Primary Care program, annual Medicare costs were 10.8 percent lower than costs projected by the Hierarchical Condition Categories, and combined VA and Medicare costs were 11.7 percent lower than projected. Observed combined hospitalizations declined by 25 percent.24

In other words, reductions in VA costs did not come at the expense of shifting costs to Medicare; instead, costs for both Medicare and the VA declined. Furthermore, patient and caregiver satisfaction was high.24

THE HOUSE CALL PROGRAM The House Call program at the MedStar Washington Hospital Center, in the District of Columbia, consists of a physician-led interdisciplinary team that includes nurse practitioners, mental health staff, and social workers. The program’s patient population is similar to that in the VA program, with a high burden of chronic disease (57 percent of the patients have dementia or chronic mental illness), substantial frailty, and functional impairment, with a high annual mortality rate.

A study that used Medicare administrative data from 2004 through 2008 in a case-control concurrent study of 722 House Call program patients with 2,172 well-matched controls found that House Call patients had 17 percent lower costs than controls. Hospital admissions were 9 percent lower, and nursing home bed days were 27 percent fewer among House Call patients, compared with patients in the control group. The cost savings were concentrated in the frailest patients.25

IN-HOME PALLIATIVE CARE PROGRAM Importantly, as palliative care programs become mainstreamed outside of the hospital in the community, there is increasing recognition of the need for home-based palliative care for patients who are seriously ill and functionally limited but not yet ready or appropriate for hospice.25 Home-based primary care programs such as those described above incorporate palliative care approaches into their delivery model. New models of home-based medical care also are emphasizing the importance of palliative approaches for people with complex chronic illnesses.

For example, the In-Home Palliative Care Program delivered in-home palliative care by an interdisciplinary team consisting of a physician, nurse, and social worker to homebound chronically ill patients with advanced chronic obstructive pulmonary disease, heart failure, or cancer and a prognosis of one year or less to live.26 The program was rolled out in two group-model, closed-panel, nonprofit health maintenance organization sites in Colorado and Hawaii. It provided pain and symptom relief, patient and family education and training, and an array of medical and social support services.

This intervention was tested in a randomized controlled trial from 2002 to 2004. Compared to those who received usual medical care, patients who received in-home palliative care reported greater satisfaction with care, were more likely to die at home and less likely to visit the ED or be admitted to the hospital, and had 33 percent lower health care costs.26

CHARACTERISTICS OF EFFECTIVE PRACTICES Home-based medical practices are successful for several reasons. They correctly target a high-cost, high-need population. They deliver a model of care and concentrate resources in a manner that is appropriate to the needs of patients and their caregivers. They also help their patients avoid using high-cost (and, in many cases, harmful) interventions such as hospital care by proactively managing issues before they result in emergencies. The practices use interdisciplinary teams to address the medical, social, and functional needs of the patients and caregivers.

Many patients cared for in these practices are near the end of life: Annual mortality rates of 20–40 percent are not unusual.9 Providing care in the home helps patients develop trusting relationships with their provider team. This facilitates the ability of practices to employ palliative care approaches for patients and offer hospice care when prognostically appropriate.9

Home-Based Medical Care Exists In A Quality Desert Ensuring that high-quality medical care is provided in the home is difficult because no widely used patient-centered quality-of-care framework exists for home-based medical care practices. The National Quality Forum (NQF) has not endorsed any measures of process and outcome that are specific to patients served by home-based medical care, in contrast to the situation of patients served in other care venues such as the acute care hospital or nursing home. The Joint Commission has an accreditation process for home-based medical practices. However, that
process is used by few practices, is expensive, and cannot be used for performance reporting in the context of Medicare payment. Previously developed quality-of-care standards for home-based primary care are relatively condition-specific and not widely used.\textsuperscript{27}

In the absence of quality standards tailored to home-based medical care, practices that are motivated to measure the quality of care they provide, for the purpose of performance reporting or to engage in value-based care arrangements, are compelled to use currently available diseasespecific quality metrics. These metrics usually do not apply to the complex health needs or even the health status of the patients of these practices and thus could create pressure to provide the wrong type of care for their patients.\textsuperscript{28–30}

For example, the use of a Healthcare Effectiveness Data and Information Set (HEDIS) diabetes measure focused on maintaining glycemic control of a specified hemoglobin A1c level has limited value in the case of a homebound and bedbound ninety-six-year-old patient who also suffers from severe dementia. In that case, achieving the measure may cause more harm than good for the patient, such as hypoglycemia and the burden of adhering to an inappropriate care regimen without any evidence of benefit, even though it helps a physician meet a performance target.\textsuperscript{28–31}

Providing high-quality care in the home is critical to achieving the goals of patient-centered care for homebound people with complex conditions.\textsuperscript{32} Accountable care organizations, Medicare Advantage plans, and Medicaid managed care plans are increasingly interested in partnering with home-based primary care and palliative care practices but do not have a method to use in advancing their understanding of whether the services they are contracting for are high quality in nature.

The National Home-Based Primary And Palliative Care Network

In response to this need, in 2013 two of the authors (Bruce Leff and Christine Ritchie) launched a national project. The goal was to form a network of organizations that would develop an appropriate quality-of-care framework and a set of quality indicators for non-VA home-based medical practices. The network would be integrated into a practice-based registry and would thus be able to engage in quality-of-care benchmarking, practice-based quality improvement, performance reporting, and comparative effectiveness research. The project was funded by the Commonwealth Fund, the Retirement Research Foundation, and the California Health-

Care Foundation.

Leff and Ritchie recruited twelve exemplary home-based medical care practices, three professional societies (the American Academy of Home Care Medicine, the American Academy of Hospice and Palliative Medicine, and the American Geriatrics Society), and three patient advocacy groups (AARP, the Henry J. Kaiser Family Foundation, and the National Partnership for Women and Families) to participate in the network. The new organization was named the National Home-Based Primary and Palliative Care Network.

Quality-Of-Care Domains, Standards, And Quality Indicators

Leff and Ritchie developed a quality-of-care schema for home-based medical care. As a starting point, the network adapted quality-of-care domains from the multiple chronic conditions framework of the Department of Health and Human Services.\textsuperscript{33}

Next, recognizing the absence of work on the quality of home-based medical care, Leff and Ritchie performed a comprehensive review of the literature in related fields, focusing on the question, “What are current domains of quality and related standards used in other care settings that might be relevant to homebound adults with functional limitations?"

Leff and Ritchie then conducted semistructured interviews with representatives of all of the network members to obtain feedback on the initial list of domains and asked them to identify relevant quality-of-care standards for either the domains identified by the study or new domains suggested by interview subjects. Based on these interviews and the literature review, Leff and Ritchie created a list of ten quality-ofcare domains and thirty-two standards appropriate for home-based medical care. They also conducted semistructured interviews with homebound older adults and their caregivers and modified the standards based on their feedback (Exhibit 1).

Next, Leff and Ritchie developed quality indicators, beginning by examining indicators that had been previously developed for other care settings to determine if some might be appropriate to use or adapt for home-based medical care. They examined quality indicators from multiple sources, as explained in the notes to Exhibit 1. They examined approximately 1,200 measures and found and mapped 286 candidate quality measures to the quality standards developed in the study. They could find no extant quality measures to map to fourteen of the thirty-two quality standards, so those were labeled gap areas.
Next, Leff and Ritchie reviewed the 286 candidate measures with representatives of the network members for an initial rough assessment of their relevance to home-based medical care. Ninety-four of the measures were viewed favorably by the network members. Measures that required changes were adapted to make them more relevant to home-based medical care. The ninety-four measures were reviewed in a RAND modified Delphi process led by another of the authors (Debra Saliba) during a one-and-a-half-day in-person meeting of network member representatives. The result of the meeting was a set of twenty quality indicators.
The twenty indicators are being tested in the field for feasibility and validity. Given the high likelihood that they will be revised in the very near term, what follows is a general description.

Ten of the indicators fell in the domain of assessment. They included assessment for pain, constipation, depression, functional status, alcohol use, preferred spoken language for health care, vision and hearing status, abuse and neglect, and risk of falls. Three indicators fell in the domain of safety: reviewing the drug regimen, addressing medications in the context of new cognitive decline, and reconciling medication changes after a hospital discharge.

Two indicators fell in the domain of quality of life: offering treatment for depression and providing influenza vaccination. Two other indicators fell in the domain of patient and caregiver experience: the provider’s ability to be caring, and his or her ability to inspire trust.

Three other domains each had a single indicator. In the domain of access, a quality indicator focused on timely hospice referral. For goal attainment, an indicator focused on the discussion of preferences for life-sustaining treatment. For care coordination, an indicator assessed timely follow-up after hospital discharge.

These quality indicators reflected measures for only seven of the ten domains and twenty of the thirty-two standards (Exhibit 1). The authors were unable to identify quality indicators from existing sets of quality measures endorsed by payers, quality organizations, and professional societies that adequately reflect the unique nature and needs of patients who require home-based medical care. Finally, we believe that our approach and quality measures are consistent with a recently described vision for better quality measurement in health care that includes a comprehensive inventory of each patient’s health and health care needs, matching interventions to those needs, and an assessment of patients’ health goals.35

Next Steps

We are testing the quality indicators in several of our network practices for feasibility of use and clinical validity. We also have developed the practice-based registry described above.

In addition, we will engage with national quality organizations such as the NQF for measure endorsement. Testing these measures in the population of patients receiving home-based medical care will provide the insights and validation necessary for the indicators to be adopted and endorsed by professional societies and quality organizations such as the NQF. For those standards for which there are no relevant measures, we are conducting a series of comprehensive literature reviews of the scientific and grey literature to inform the development of new quality indicators for testing in this population.

Conclusion

Homebound older adults have been a relatively invisible patient population from a quality and care delivery standpoint. The inability of homebound patients to access usual medical care because of multiple chronic conditions and both functional and social challenges requires a medical care delivery model that sees them on their terms in their place of residence. It also requires valid quality measures to improve care delivery and linked financial models that are appropriate and accountable. The authors and network members hope that the work described in this article will bring the field of home-based medical care one step closer to integration into routine health care practice so that homebound older adults can get the high-quality care they need. ■

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NOTES

3 Congressional Budget Office. High-


7 Unpublished data provided through contract to the American Academy of Home Care Medicine.


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